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Public involvement practice in the National Health Service : narratives of power, resistance and partnership

"Public involvement practice in the national health service: narratives of power, resistance and partnership"

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Abstract

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Introduction

Public involvement has become a central theme of national health service policy in recent years, driven by change in society and management practice, but achieving progress in public involvement has been slow and it has conflicted with other policy areas such as performance management. There has also been resistance from both managers and health professionals who have a vested interest in maintaining control of health service decision-making. Changing notions of accountability, citizenship and power are crucial to understanding the development of participation as a theme of government policy. Most recently, I argue that significant change in health policy has originated in cross-cutting initiatives which have introduced powerful new perspectives into the NHS.

Methods

This research uses a mix of methods to develop an understanding of public involvement practice in the NHS. An initial survey of health authorities established a baseline in 1998 and was followed by three qualitative case studies of public involvement in differing contexts.

Results

In 1998, all health authorities undertook work that they regarded as public involvement and many had developed organisational structures which could enable involvement to take place. However their work was limited in scope, appeared under-funded and was not often integral to planning and policy-making processes.

Case studies of public involvement in a three different settings found citizens and service users were willing and able to participate in policy-making, and could do so effectively when conditions were right. There was scepticism about their voices being heard and their confidence in the process remained fragile. NHS managers were often unprepared for the consequences of involvement although there appeared to be a cadre of managers who valued it greatly. Health professionals took little part in the process and were often critical of what they characterised as the unrepresentative views of those who became involved. The prospects for involvement appear to depend on embedding it within the health service and connecting it more coherently to decision-making. The increase in partnership arrangements that involve the health service and the local public in regeneration and other area based initiatives have exposed health decisions to more local involvement. It may be these developments, rather than the structures created by the NHS for public involvement that are more effective in bringing about the necessary change in approach.

Acknowledgements

A project like this one is the product of long hours of work and depends on the support of many people. I would like to record the huge debt I owe to all those who have helped to bring this piece of work to its conclusion.

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I could not have begun this research without the support of Kieran Morgan who was a very understanding and generous employer at Avon Health Authority. I like to think that they benefited from my work, but I'm not always sure that was the case. Also, I want to acknowledge the contributions of Liz Anderson and Chris Salisbury, co-researchers on the Knowle West case study and my fellow PhD student Rosie Rowe with whom I collaborated on related research. These three helped so much to develop my ideas.

Lastly, I want to mention how grateful I feel to all of those who consented to be interviewed, allowed me into their meetings, returned survey forms or took part in focus groups I really could not have done it without them!

Author's Declaration

"I declare that the work in this dissertation was carried out in accordance with the Regulations of the University of Bristol. The work is original, except where indicated by special reference in the text, and no part of the dissertation has been submitted for any other academic award. Certain parts of this work were undertaken in collaboration with others, their contribution is acknowledged in the text. Any views expressed in the dissertation are those of the author."

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"Public involvement practice in the national health service: narratives of power, resistance and partnership"

Arguably, the emergence of public involvement as a theme of health policy in the UK can be traced to the publication of "Local Voices" by the NHS Management Executive in 1992. Local Voices called for health care purchasers to listen to, inform, discuss and report back to local people in the course of planning service change. The development of this kind of dialogue with citizens marked a break with previous practice of one-off consultation. This conception of local people as partners in health decisions was itself a break from the government's primarily economic model of health care in which the "patient" is a consumer of health care goods.

There are a number of explanations for the emergence of public involvement as a theme of policy. Some cite the growth of a consumer society (Department of Health, 2000), while others refer to a breakdown in trust in society, the dysfunction of democracy or the failure of top-down models of planning to produce public services of adequate quality (Perri 6, 1997). Whether people who use services are viewed as consumers, clients, patients, users or customers depends on the role in which they are cast by the health care system and the ideology of the government in power. Consumers are fundamentally economic beings who make choices among competing providers. Citizens can be conceived as partners in government, clients draw on professional expertise and services for their own needs, but patients are dependent on professionals as decision-makers. That said, Local Voices and subsequent policy guidance (NHS Executive, 1994; Department of Health, 1997;2000) really fail to distinguish between the role of the citizen and that of the consumer. Hirschman's (1970) distinction between exit and voice, and Saltman's (1994) distinction between the economic and the political both highlight

the competing models of involvement, but these are repeatedly conflated by policy documents. A further distinction is I believe necessary, between a bureaucratic approach to involvement, in which people are expected to conform to rules and "fit" their involvement into current models of service provision and organisation and an empowerment approach (Barnes & Walker, 1996) in which services and organisations are open to remodelling in partnership with service users and citizens.

In this dissertation, I will explore how the NHS in the UK has implemented the policy of public involvement in health decision-making and the extent to which central policy guidance has led to local action. Writing in 1993, Charles and DeMaio concluded that participation in health care decision-making had not been adequately evaluated. More recent research suggests that the evaluation of public and service user involvement remains inadequate (Rutter et al, 2004), despite a growing literature on the subject (Thompson et al, 2001).

Terms like consultation, involvement, partnership and participation tend to be used more or less interchangeably in the literature. However consultation is a term that carries an implication of retention of power by the state over both process and outcome. Consultation is a formalised form of mandatory participation. There is no implication that the power over decision-making is ceded to any group. Partnership, however does carry an implication of shared power and decision-making (Cawston & Barbour, 2003). Both involvement and participation are broader and more or less neutral and non-specific terms referring to the role of individuals and groups in the planning and management of health services, initiated by health service organisations. It is this language that is most often used in policy documents in this context in health, perhaps for that reason. (Putland et al, 1997; Rutter et al, 2004)

Similar debates occur over the terms public, citizens, users and, in health, patients. Both patients and users are terms referring to defined groups who are, or have been involved with services. Patient in particular implies passivity in relation to the professional and carries the acceptance of the medical model of health, user on the other hand is a term often chosen by those who are involved with services.

Public and citizen imply wider, universal groups who may, or may not have current therapeutic involvement with services, but have an interest in health decisions by virtue of their residence and/or citizenship. Policy documents in the NHS tend to use the terms patients and public, rather than users or citizens although users is sometimes favoured in the context of mental health, learning difficulties and physical disability.

It is useful to distinguish at this point between public and private involvement. Private involvement refers to the participation of individuals in decisions about their own care and treatment, while public involvement refers to their part in decision-making concerning policy development, service planning and delivery. I will concern myself only with public involvement, while recognising that many of the same forces that impact on the involvement of the public in health decisions are equally if not more relevant to individuals in their participation in decisions about their own care.

In Chapter 2 I will examine public involvement policy development at the national level. In this Chapter, I concentrate on the period between the 1990 reform of the health service following the White Paper "Working for Patients", which marked the emergence of public involvement as a key policy theme in UK health policy (Department of Health, 1989) and the NHS and Health Care Professions Act (2002). There is a clear division between the policy pursued by the Conservative governments of the nineties and the New Labour government since 1997.

The next Chapter will review other literature relevant to public involvement, establishing the theoretical underpinnings and outlining my intended approach to the analysis of public involvement practice. Central to the understanding of involvement in decision making are issues of power and accountability. At the root of participation must be a desire to create a more pluralist approach to decision-making, acknowledging the inequalities in power among stakeholder groups. Together with this, the notion of a service that owes accountability to a higher power, that of the electorate or citizens. I will be focusing in particular on three areas of theory: accountability, citizenship and democracy, and power. These three are enabling or disabling influences on the growth of public involvement in the contemporary health service.

Chapter 4 deals with the research methodology. In this Chapter, I will describe my approach to the research. I will also argue that the influence of the dominant epistemology and research methodology in the health service extends beyond considerations of researchers and has a profound influence on planning and decision-making.

Chapters 5 to 8 detail my original research. In Chapter 5, I discuss a national survey of health authorities in England and Wales, which served to provide evidence of the progress made in the development of public involvement in the period 1989 to 1997, the period of Conservative administrations. The survey came at a time when the role of health authorities was being taken on by new primary care organisations, so it describes the extent of development of public involvement at the end of that particular managerial regime. Following on from the survey, I undertook three case studies of public involvement practice in different situations. The case studies were chosen to cover common situations for involvement, as found in the survey.

Chapter 6 describes the involvement of local citizens in major strategic decisions in an NHS Trust area. The Trust concerned, in their first major programme of public involvement, used a range of approaches to gather local views about plans to modernise their facilities and develop a new model of care based around very specialist services supported by a network of community health centres. The programme was well planned and successful in that it reached a large number of people. In this Chapter, I discuss the successes and the ultimate failure of the Trust to involve local people in their decisions.

The next case study also involves people participating in decision-making as citizens although in other respects, it is quite different. Chapter 7 concerns involvement at a very local level in planning the development of an innovative primary care facility designed to bring together health premises with community resources in an area of poor health and poverty in South Bristol. Public involvement was very much part of the original philosophy of the project and in this Chapter, I will outline how local people were involved in the development of the health park. Despite problems along the way, there continues to be local involvement in a number of different ways.

In the third case study, I switch attention from people as citizens to the involvement of service users. Chapter 8 is about the involvement of people who have used mental health services in decision-making in an NHS Partnership Trust. This is an organisation that brings together health and social services provision. While there appears to be a significant amount of involvement, including for some time participation in the Trust Board, it appears that only at a very local level can service users really influence decisions. Even where they are involved in statutory groups, their influence is reduced by the way in which processes are managed by the Trust.

In the final Chapter of this dissertation, Chapter 9, I develop an overarching analysis arising out of my research, draw conclusions and make suggestions for future research in this area. In this Chapter, I develop my analysis of the successes and failures of public involvement in the contemporary health service and offer a view on the likely success of the current arrangements. In this chapter also, I return to the ideas that arise first in my discussion of the literature and policy and then re-occur throughout the three case studies. These are power, resistance and partnership. I discuss how the three concepts can be applied in the context of public involvement and I conclude that these are ideas are fundamental to the understanding of the contemporary position of the public and service users as well as professionals and health managers in decision-making.

Chapter 2: The Development of Public Involvement in the Health Service

2.0 Introduction

The purpose of this Chapter is to situate the growth of patient and public involvement in the context of relevant legislative and policy developments in the health service and elsewhere. In the next Chapter, I will examine the literature relevant to the study at a more theoretical level in detail, but first I will try to tell the story of public involvement over the last two decades. I will focus primarily on the period since the 1989 White Paper "Working for Patients" although in order to do so it is important to include a discussion of the Griffiths management inquiry which reported in the early 1980s and to cover briefly the work of Community Health Councils which were the first organisations to be established with the purpose of bringing public views into health service decision-making.

I will outline three stages in the development of public involvement in the NHS at a national level and their importance in terms of the development of public involvement (see Table 2.1). The three stages are a pre-1989 phase, before the major reorganisations of the NHS following the "Working for Patients" white paper, the post re-organisation phase under Conservative administrations from 1989-1997 and the post 1997 phase under new Labour. At the end of the chapter, I describe and assess significant examples of the practice of public involvement in decision-making from local health communities.

Table 2.1 Key Policy Developments in Patient and Public Involvement in the NHS1974-2002

Date	Policy Development
Pre - 1989	
1974	Community Health Councils founded in the NHS reorganisation of 1974
1985	Griffiths Management Inquiry introduces General Management

1989-1997 Thatcher and Major Governments	
1989	Working for Patients – the internal market, purchaser-provider split, local representation removed from NHS Boards
1991	Patient's Charter – Rights to NHS treatment outlined for the first time
1992	Local Voices – Health Authorities to become "Champions of the People"
1995	Mawhinney Review finds that only on in four Health Authorities is "doing well" on public involvement, re-launches Local Voices.
1995/96	Planning and Policy Guidelines – Patient and Public Involvement cited as one of the main medium term top priorities
Post 1997 New Labour Government	
1997	The New NHS – Modern and Dependable
1997	The Patient Partnership
2000	The NHS Plan
2001	The Kennedy Report
2001	Patient and Public Involvement in Healthcare
2002	NHS and Health Professions Act – CHCs abolished, new structures for involvement introduced

2.1 Public Involvement in the NHS before 1989

The view commonly held at the time of the founding of the NHS was that citizens were equally entitled to participate in society, but that their participation could be undermined by ill health, poverty and ignorance among other factors (Milewa & Valentine, 1996). Participation in decision-making was seen as a part of representative democracy, in which government funded social welfare programs were upwardly accountable to parliament. For the average citizen, participation would certainly mean voting in national and local elections and taking part in other activities such as participation in organisations with political aims such as trade unions, pressure groups and political parties.

For the first 30 years of the NHS, the general public's role was purely the receipt of services. Only lay members on hospital boards participated at any level. Their role was primarily administrative, while the development of health policy was the province of the medical profession (Eckstein, 1960).

Disturbances to the domination of the policy arena by the medical profession in the 1970s have been attributed to a number of factors, including the growth of trade union militancy over pay beds and long term care (Klein, 1989) and the growth of patient organisations (Sang,1998) although the deteriorating economic situation at the time also led to pressure on public spending, including health service funding (Klein, 1989).

The growth of organisations concerned with health issues took place on many fronts, with prominent developments in maternity care through the Maternity Alliance and in chronic illness such as the Parkinson's Disease and Multiple Sclerosis societies. Often, these groups were supportive of, and supported by medical professionals, whom they saw as in common cause, seeking increased funding for treatment. But there were also developments that questioned medical orthodoxy from academics (Illich, 1977; McKeown, 1979), while some users of services challenged prevailing medical definitions of their health and often questioned the value of medical responses, preferring to emphasise social definitions or holistic treatments and to campaign for civil rights (Salter, 2002).

A series of academic critiques of the of professional domination of health care contributed to the de-mystification of medical knowledge (Illich, 1977; McKeown, 1979; Friedson, 1970) while high profile failures of medical science (for example thalidomide and Ely Hospital) led to a growing a scepticism about the scientific/medical establishment, shared across the political spectrum (Webster, 1998). Such a trend can also be viewed as a part of a wider phenomenon in which the public trust of science as synonymous with progress was shaken by authors such as Rachel Carson (1999) and E.F. Schumacher (1973) who highlighted the environmental consequences of technological change. Davies and colleagues point out that

At the start of the twentieth century, there appears to have been a general assumption that doctors, police officers, teachers and other professionals were the experts, whose judgement was to be trusted, and who were therefore left relatively unchallenged to carry out their duties. By the end of the century this culture of public trust had been severely diluted, as an increasingly educated, informed and questioning public sought reassurance that its taxes were being well spent. (Davies et al, 2000 p1-2)

The medical profession's ability to shape health policy rested on confidence in the potential for medical technology to reduce illness, which was supported by their position of third dimensional power built on the monopolisation of knowledge resources. In the industrialised post-war world, the definition of health was firmly associated with technological acute medical care, requiring high levels of skill and specialised knowledge. This served to further legitimise the right of the professional elite to monopolise policy making at national and local levels (North, 1997).

The task of matching expressed demand for health care with the supply of care was perceived as essentially technical, rather than political and was delegated to a professional-technical elite which would act within a financial and legislative framework laid down by the representatives of the people in parliament (Salter, 1998; Ling, 1999). Change in health care was incremental, without radical shifts in policy. Policy-making was centralised and consensual within this closed community, of government, bureaucrats and doctors with little input from outside. Local services existed to implement policy and deliver services to the largely passive population. Crucial to the existence of this "concordat" was the government and public perception of the legitimacy of the doctor as a trusted professional and unbiased arbiter on clinical matters. Should the doctors lose government or society's collective confidence as a result of the growing criticism, the consensus itself would become unstable.

By 1974, there was a consensus for change, including public participation in decision-making (Klein, 1989). Models emphasising the representation of local communities were favoured on left, and the interests of the service user as consumer on the right. The incoming Conservative Government enacted reform concentrating on managerial efficiency. Separation of the management of health services from the public participation was part of the plan with lay representatives on health authorities and the independent health "watchdog" Community Health Councils.

Community Health Councils – "poodles that should be rottweilers"

The CHCs established by the 1974 Act remained virtually unchanged until their abolition by the NHS and Health Professions Act in 2002. The Councils were composed of representatives nominated by the local authority, the voluntary sector and members appointed by the Regional Health Authorities. Their functions included inspection at hospital and health service premises, but their principal power was their ability to request that the Secretary of State review planned changes in local service.

CHC's were small poorly funded organisations prevented from undertaking major pieces of work or large-scale programmes of public involvement by their lack of resources. They also lacked a public profile, (Klein & Lewis, 1976) and were criticised as white, middle aged, middle class organisations, out of touch with the wider community (Cooper et al, 1995). Indeed, it was never quite clear whether they represented the whole community or only the sectional interests involved (Pickard, 1997). These factors served to minimise the impact of CHCs at a local and a national level (Lupton et al, 1995; Cooper et al, 1995).

Following the reforms of 1990, their role was subverted by the health authorities who were urged to develop more effective means for involving

the public their work directly (NHS Management Executive, 1992). This meant that the CHCs were no longer being seen as the principal voice of the local public, merely on of many "local voices" (Pickard, 1997). The marginalisation of CHCs was completed by guidance which gave the health authorities the option to "invite" them into the purchasing process and gave them only observer's rights at health authority meetings (Lupton et al, 1995).

Nevertheless, some health authorities developed positive relationships with their CHCs, in some cases contracting public involvement work to them (Bristol & District CHC, 1996). A 1991 survey of CHCs confirmed that the goodwill of local managers was increasingly important and that CHCs which adopted adversarial postures were likely to be excluded altogether (ACHCEW, 1991). One study found that CHCs were variously partners; consumer advocates and independent challengers to health authorities (Lupton et al, 1995) and that opportunities for involvement in planning were greater for partners than other forms. The more independent Councils were not automatically included in planning or policy making, but had to press the authority to be sent relevant documents. Health authority managers tended to see CHCs as not critical *enough* (Cooper et al 1995) and sometimes less important as consultees than other health interest groups (Shepherd, 1995).

Both Cooper and Lupton's research suggests that CHCs were peripheral to decisions on policy direction and had only limited influence on policy details. The NHS Reform and Health Care Professions Act (2002), finally abolished CHCs. This Act created new arrangements for public involvement in the NHS, with the inspection powers of CHCs being taken on by to "Patient's Forums" and the referral powers transferred to local authority Oversight and Scrutiny Committees.

The Griffiths Report – "The supermarket model"

If the CHCs failed to live up to the role of public advocated in the health service, an alternative approach to public involvement was suggested in the mid-eighties that took its cues from the activities of private industry. The impetus for the development of a culture of consumerism among health service managers emerged from the Griffiths Report (1983). Sir Roy Griffiths was tasked by the government to recommend improvements in the management of the health service. The effects were far reaching for managers as they were encouraged to apply the practices of the private sector to managing public services.

Roy Griffiths, an ex-miner and then Managing Director of Sainsbury's was approached to chair a review of management of the NHS in 1982. He had been identified by those close to Margaret Thatcher, the Prime Minister as an important factor in the commercial success of the Sainsbury's (Wistow & Harrison, 1998). The initial remit for Griffiths was vague and confused (Webster, 1988), referring to "manpower levels" as the principal concern. However Griffiths re-defined the role and eventually the review covered many aspects of NHS management and resource use.

The small review team was composed of business leaders who relied for evidence on official reports, the opinions of those they met during extensive visits to hospitals and a commissioned a study of doctor-manager relations. The report, issued in October 1983 came in the form of a letter from Griffiths (and written mostly by him) to the Secretary of State, Norman Fowler.

Far from being a comprehensive plan, the report offered little more than "bright ideas" in Harrison and Wood's (1999) term. Griffiths was critical of what he saw as the absence of management in the services *"...if Florence Nightingale were carrying her lamp through the corridors of the NHS*

today, she would almost certainly be looking for the people in charge." (Griffiths, 1983: p. 22). In addition to leadership, he called for modern management, including performance assessment for responsiveness to "consumers" or service users. *"Whether the NHS is meeting the needs of the patient, and the community, and can prove that it is doing so, is open to question"* (Griffiths, 1983: p.10).

Recommendations were for strong general managers at each level of the NHS, with the discretion to take decisions concerning their own units. Doctors would also be recruited to management roles, through managing local workload–related budgets. The strong support from the Prime Minister led to speedy implementation, despite significant opposition from the BMA and nursing groups. The Griffiths report could be seen as a way to disturb the comfortable policy community by dramatically increasing the power of the manager, and their role in health policy to challenge the hegemony of the clinicians.

Griffiths' views on the functioning of organisations were that managers should focus on what the service looked like from the point of view of the customer, while he also possessed *"a fairly simple-minded belief in rationality"* (Wistow & Harrison, 1998: p. 665) which perhaps led to the conclusion that the lack of a chief executive was a cause rather than a consequence of the power of the professions.
This naiveté, if that is what it was, became the precursor to significant cultural change as the business culture of general management asserted itself. For some of the professionals, especially for nurses, the power to veto developments was lost (Klein, 1989). But the medical profession resisted the advance of general management and the implementation of the review in the face of opposition from the professions became a significant problem (Strong & Robinson, 1990).

By raising the status of managers, the state signalled a belief that they could deliver the conflicting objectives of growth in services and public spending limits. Bringing managers into this arena, previously the sole responsibility of clinicians, moved issues of rationing services from the surgery into the open domain of the NHS, introducing new problems of accountability and legitimacy. In the event that care was rationed, the doctor could appeal to clinical decision-making and the social neutrality of professionalism. The manager on the other hand had to rely on organisational structures, accountability to parliament and to the local population (Salter, 1998)

If for government, Griffiths signalled a new way to deliver savings and growth, for the health service it brought new approach to the management for the service as a whole. The influences were private sector models rather than the professionally dominated consensus that had prevailed in the past. The "new public management " approach has been described as a diffuse ideology, with a number of variants, but which privileges commercial models of organisation and management practice in the context of public sector services (Cairney, 2002; Hood, 1991). Where previously there had been only "patients" to treat, the new approach advocated responsiveness to "consumers", without being specific as to what that implied. However the dominant discourse was now rooted in the economics of consumption, with individual consumers' needs to be satisfied by efficient, and effective health care providers.

2.2 Public Involvement in the Thatcher and Major Governments

The development of general management within the NHS, following the Griffiths Report was a crucial step in the application of the Thatcher Project to the health service. The process of reform continued at the end of the 1980s as a reorganisation of the service was contemplated.

Working for Patients and the 1990 NHS and Community Care Act

The White paper "Working for Patients" followed a series of policy papers from think-tanks closely aligned with the Conservative Party, which asserted that the market could be utilised in the provision of health care (Letwin & Redwood, 1988). As with the Griffiths report, the Prime Minister's review was undertaken by a small group of advisors and without the participation of the professional organisations. Some have seen this as a more direct challenge to the powerful medical profession who were known to be hostile to market-based health services, or as a further attempt to destabilise the traditional policy community in the health service (Salter, 2003; Day & Klein, 1992)

Whether this represented the final nails in the coffin of the post-war consensus in the NHS (North, 1997) is debatable as while the implementation of the reforms progressed, the pragmatists in the Government tended to return to cooperation with professionals and the rebuilding of the policy community became essential to achieving the policy aims (Salter, 2003). However the nature of the relationship between the profession and the government had changed. Marsh and Smith (2000) cite four reasons why policy networks change; economic change, ideological change, political change and knowledge-based change. While elements of these four can be identified, the main pressure for change in this instance was ideological, with the medical establishment identified as an obstacle to the Thatcherite drive towards a cheaper, more efficient public sector.

The approach outlined in Working for Patients featured an "internal market", an approach developed by the American economist Alain Enthoven (1985) to introduce market discipline to the NHS while maintaining it as a public sector organisation. In the internal market, the money should follow the patient and successful providers would prosper, while unsuccessful ones would be encouraged to adopt more efficient

approaches to care. The patient/consumer could, through their agent (the GP or health authority) exercise the power of choice or exit over the market. So the passive patient could be seen as evolving into the active consumer as Griffiths had wanted and health care shifted from public service towards the marketplace.

A problem for this approach was that as a public service, there should be a level of accountability. In previous models, this had been through the bedpan philosophy to Westminster, but markets are decentralised institutions and self-regulating. Consumerist notions of accountability which use market forces to guarantee that need receives adequate response were viewed by writers like Waldegrave (briefly Secretary of State for Health) as superior to more unwieldy political mechanisms (Waldegrave, 1993).

The 1990 NHS and Community Care Act (Department of Health, 1990) which followed the White Paper, created an internal market by separating the planning and purchasing of healthcare from provision of health services. Health authorities took on the purchasing role, assessing the healthcare requirement of the local population and seeking to make agreements with providers to supply it. On the provider side, NHS Trusts were established to provide services, theoretically competing with other providers for a contract to provide health care. Greener (2002) follows Ham (2000) in concluding that the internal market was a means to the end of increasing managerial control over the NHS. Both writers conclude that the real architect of the reforms was the practical Ken Clarke, rather than the academic Enthoven and that their main impact was that managerial interests were further promoted to challenge professionally led health policy formation. From this perspective, it is difficult to see the emergence of a strong consumer interest, except to the extent that the preservation of a publicly funded health service remained a prerequisite for electoral success (Greener, 2002).

At a local level, health organisations were run by Boards of Directors including executive members and appointees of the Secretary of State, but without any other representation. The absence of representatives of local communities from Boards was interpreted as contributing to a "democratic deficit" in the local governance of health services (Cooper et al, 1995). Appointments to NHS Boards were entirely under the control of the Secretary of State and were widely criticised as politically biased, removing opposition from the decision-making bodies. In 1995, a report by the Independent newspaper found that most NHS Trust chairs had links to the Conservative Party (Cooper et al, 1995).

However, contemporary debates do not limit deficiencies in representation at local level to the health service or to this particular legislation. Docherty and colleagues (2001) put the growth of interest in participation down to a crisis in confidence in the ability of either the state or the market to create a cohesive and economically successful society. They argue that participation has appeal across the political spectrum, though the right emphasises individual and the left collective notions. Britain has been called a "low trust" society in which representative democracy is viewed as increasingly inadequate (Perri 6, 1997) and participation is viewed as a response to the decline of local electoral politics, securing a renewal of democracy at local level through participation in the process of government.

According to Stewart (1997) the development of new forms of democratic process in local government, including devolved local administration, tenant representation in housing management and citizens' panels is a result of a loss of confidence in the effectiveness of the electoral process as a mechanism for accountability. Others agree, citing the growth of agency government and quasi-autonomous non-government organisations (Burton & Duncan, 1997). So we can relate ideas of democratic deficits to

both a specific debate about the governance of health services **and** broader debates about democracy and citizenship. It can also be argued that debates over accountability are not only about the effective functioning of the system, but have a political dimension concerned with the values embodied in the system. A more democratically accountable form of decision-making will make the process and the outcomes more acceptable. Where the process for making decisions is accepted, even decisions with which actors might normatively disagree will be accepted as a result of their having been arrived at through an accepted process (Salter, 1998; Harrison & Mort, 1998; Held, 1989).

Harrison and Wood (1999) conclude that the 1990 reforms, like Griffiths owe more to "bright ideas" than detailed planning. The White Paper, offered little more than a sketchy outline of the future organisation of the internal market or the role of the purchasing health authorities leaving the detail to be developed on the ground by managers in NHS Trusts and health authorities. What it did provide though was the intellectual basis, the body of understandings on which the reforms would rest. Role of the patient or consumer was one that remained to be finalised although theoretically, accountability to the "sovereign" consumer, rather than the citizen was the acknowledged model.

The Patient's Charter

The Patient's Charter was introduced in 1991 and revised in 1995. The Charter's aim was to codify the rights of patients being treated by the NHS and establish a national standard of quality. It was developed by the Government, without significant consultation with patients, patients' groups or professionals on either the rights to be expected or the standards of care in terms of waiting times.

The rights outlined by the charter included the right to receive health care, register with a GP and be referred to secondary care. Some of these, such as the right to treatment of the basis of need, were already assumed by most people and none had any statutory status. They have been called *"a hotchpotch of well-intentioned, but ill-informed objectives that health care providers were required to meet"* (Crinson, 1998: p. 234; Calman & Gabe, 2001).

Research suggests also that knowledge of the Charter or of the rights was sketchy (Farrell, 1999; Tailor & Mayberry 1995; Hughes & Griffiths, 1999). Farrell found very little knowledge of the Charter among patients, but more among NHS Staff. Both groups were critical of its impact and usefulness. More than anything, staff and patients agreed on the need for a revised Charter to involve patients and staff in its development. (Farrell, 1999) But while some see the Charter as a seminal event, marking *"precisely the kind of shift of power from providers to consumers"* envisaged by Griffiths and the 1990 reforms (Klein, 1995: p. 213), it has also been argued that the Charter was actually little more than a mechanism for re-establishing central control over NHS providers as the Charter standards represented a means for assessing the central goals of efficiency and effectiveness, rather than the responsiveness to the consumer.(Crinson, 1998) Despite these different perspectives, both Klein and Crinson conclude that the consumerism of the Charter was of a top-down kind, a way of government reining in the power of managers in NHS Trusts in the name of the consumer (Crinson, 1998, Klein, 1995). Even in this, the Charter failed as the creativity of managers stretched to ensuring that Charter standards were met by for example using nurses as receptionists in accident departments to ensure that all patients were assessed soon enough after arrival. (Crinson, 1998)

The development of "purchasing" health authorities was initially overshadowed by other changes however by the beginning of 1992, the NHS Management Executive (NHSME) had begun to focus on the activities of the Health Authorities and their relationship with local communities. The publication "Local Voices" (NHS Management Executive, 1992) is often taken as the beginning of the development of the model of public involvement in local health decision-making.

Local Voices – "The Champions of the people"

Local Voices cited examples of widespread activity that had already begun at health authorities (Sabin, 1992), however this effort was far from universal and only one in five authorities were regarded as "doing well" in this area in a Departmental review two years later (Cooper et al, 1995). This brief paper proposed that local health authorities would act as "Champions of the people" in commissioning health care from NHS Trusts.

Local Voices called *for "...a radically different approach from that employed in the past. In particular, there needs to be a move away from one-off consultation, towards on-going involvement of local people in purchasing activities"* (NHS Management Executive, 1992: p.2). It explicitly defined local people as including different local populations, service users and the leaders of local opinion. The health authority role was seen colourfully as "champion of the people", and their decisions should reflect, so far as practical, what people want, their preferences, concerns and values.

The essentials for local involvement were set out as listening, informing, discussing and reporting back. All with the aim of giving people an opportunity to influence the debate at critical stages. The benefits of this work were not limited to the enhanced "credibility" of the local health

authority, but also could include better services and would improve the position of the authority in negotiations with providers.

Health authorities were told that this should be more than "going through the motions" and that while there would be pitfalls in terms of time constraints, raised expectations, and lack of knowledge for example, these should be real discussions and if things do not change as a result, or the health authority ultimately decides against the public's expressed view, local people should be told why. There were also examples of techniques that were already employed by some, including public meetings, focus groups, forums, telephone hotlines and surveys, without suggesting that it was providing a prescription or blueprint.

The implicit recognition that what had passed for "public consultation" lacked credibility and amounted to window dressing appeared to be a strong message that the NHS Management Executive was also taking this seriously. However the other message of Local Voices was that the local public were only one of a number of sources of evidence to be used in decision making, and that others, including epidemiological data and the views of opinion leaders could over-ride local opinion.

What was clear from the examples identified in the paper was that there was already significant activity. Sabin (1992) had found health authority managers concerned with local legitimacy of decisions. Their solution had been to "cultivate legitimacy" through familiar methods like surveys and public meetings or by working closely with the CHC who, despite fifteen years of experience in contributing to local health debates were regarded as one of many voices by the Management Executive.

Following soon after the Patient's Charter, Local Voices was criticised as another meaningless example of consumerism and an unrealistic attempt to involve the public without first establishing the boundaries for

participation or establishing structures to make participation effective (Pollock, 1992). However, far from being purely consumerist, it appeared that the debate had moved beyond responsiveness to the consumer, to a new dimension in which health authorities viewed accountability in political as well as economic terms. More valid criticism was that the choice over how much to involve the public was entirely the health authority's to make, there was no right for the local community to expect a given level of participation, nor were there ground rules for the authority to follow in using the results (Cooper et al, 1995). Also, the participation envisaged kept the public at arms length, it was indirect and passive in form in which the public as citizens or service users should wait to be asked to give their views. At a deeper level, Local Voices failed to acknowledge, as had Griffith in another context, the power relations in the health service, especially the power of the professional bodies to shape public opinion (Milewa et al, 2002).

Although policy makers would return to the theme a number of times (Bottomley, 1994;Mahwinney, 1994; NHSE, 1995), consistent or detailed support from the NHS Executive or the Department of Health was largely absent at that time. An early evaluation by the Department of Health was reported to Health Authorities in 1994. The Minister for Health, Brian Mawhinney identified a fifth of health authorities as making good progress, with a further fifth as making poor progress. The basis for the assessment was not revealed in detail although "good" practice was acknowledged to include tangible change as a result of the activity (Cooper et al, 1995).

In re-launching the initiative, Mawhinney stressed a number of reasons to develop public involvement further; to gather local views about services; that early involvement can reduce later opposition; that health authorities need to establish local legitimacy for their decisions and that the public need to be informed and educated about health services (Mawhinney, 1994). Although gathering consumers' views about local services fits

comfortably into the "market research/consumerist" approach to public involvement and is aimed at developing quality services within a centrally defined framework as advocated by Griffiths and implicit in Working for Patients. Mawhinney goes beyond that, confirming legitimacy goals and noting educational and public relations functions also so the implication was that the narrow consumerism associated with the 1990 reforms had broadened considerably.

The Mawhinney review documented activity across the country, including examples of "good practice" in involving the general public or service users. These confirm a range of approaches underway, including "health panels", focus groups, individual interviews and community development work (NHS Executive, 1994). An independent assessment of Local Voices was published by Cooper and colleagues (1995) at the IPPR Think Tank. They conclude that the purpose of involvement varied from authority to authority but that the majority of work was aimed at "consulting the public", rather than enabling them to contribute more actively to policy debates. IPPR also found also that much of the work was concerned with marginal issues and where professional opinion conflicted with the views of the public, the views of local people were overridden. The Review could not document examples of where specific change to existing plans came about as a result of the involvement work, but some valuable lessons were learnt (for example one Health Authority comments *"The report became available to late to have a significant impact on the purchasing plans"* (NHS Executive, 1994:p. 12).

Priorities and Planning Guidance, 1996/97

When the NHS Executive announced its medium term priorities for the development of the NHS over the subsequent three to five years in June, 1995, included as one of the six highest priorities was

> *"To give greater voice and influence to users of NHS services and their carers in their own care, the development and definition of standards set for NHS services locally and the development of NHS policy both locally and nationally"* (NHS Executive, 1995: p. 9)

Health Authorities would be assessed on four milestones, strategy and the development of a systematic approach, demonstration of the influence of local people and other groups, a systematic approach to 'partnership' with individual patients and responses to complaints.

It could be argued that the other priorities, including developing primary care and the cost effectiveness of services may have carried more weight in Whitehall although the official line was that no priority had any greater or lesser importance (NHS Executive, 1995). In fact, barely a year into the planning period and before the first annual evaluation, the government was engaged in a losing election campaign.

What it does represent however is a further significant shift from Waldegrave's (1993) perception of accountability to the consumer through the market to a position in which the local public is seen as partners in the production of health policy.

Assessing Public Involvement before 1997

Although there were times when the strength of the rhetoric appeared to indicate that the government was committed to involving the public in health decisions, these times were few and far between before 1997. The Griffiths report and the internal market appeared to promote a consumerist form of involvement in the NHS, but pointed more to the growth of managerial influence in health policy.

Policy on public involvement was weak, both in terms of its priority for the Secretary of State and in terms of its drafting. There was a noticeable

broadening of the base of policy documents to encompass more than a consumerist approach, but none recognised differences in the form of public involvement, for example none differentiated service users from the general public, or direct involvement from indirect (Richardson & Bray, 1987).

The Planning and Priorities Guidance for 1996/97 came too late to have any real effect, but by the time of the change in government, but what real progress that had been made was largely as a result of local action in health authorities (Shepherd, 1995; Bowie et al, 1995; Sheffield Health, 1997; Milewa & Valentine, 1996). From the early days of the internal market, some health authorities began developing public involvement in a range of forms. In Somerset for example, local health panels regularly took place around the County. Randomly selected citizens, chosen to be statistically representative of the local population were engaged in group discussions about policy issues and the results of their discussions reported back to the health authority (Bowie et al, 1995). Bromley and Bristol and District developed broadly similar approaches, involving existing voluntary groups in discussions about annual plans (Milewa & Valentine, 1996; Burton, 1994; Shepherd, 1996) and in Bath and elsewhere, approaches modelled on that of the State of Oregon tried to identify the public's health care priorities using questionnaire surveys or interviews (Richardson et al, 1992; Ham, 1998).

Later in the 1990s, the idea of Citizen's Juries was developed by the Kings Fund, using models from the USA and Germany (Sang, 1998). In a quasi-judicial manner, the juries considered evidence and issues in depth over several days, before coming to a judgement about the issue. Although juries considered a range of issues, in no case was the authority concerned willing to devolve decision making power to the jury, all taking the reports as one piece of evidence among many (Sang, 1998).

2.3 Public Involvement after the 1997 Election

Patient and Public Involvement and the NHS Plan

The election of the Blair government in 1997 was accompanied by the promise of further change in the NHS. The internal market and GP fundholding were quickly laid to rest without mourning, but perhaps more far reaching reforms included the emergence of discourses of 'modernisation', 'partnership' or 'joined-up government' that ran through policy initiatives right across government (Matka et al, 2002).

The NHS Plan (Department of Health, 2000) was published in July 2000, following a four month period of "consultation" during which NHS staff, professionals and patients 'contributed' to the Plan. Following a budget that had guaranteed growth in NHS budgets, the NHS sought to "modernise" a service that had *"...failed to keep pace with changes in our society"* (Department of Health, 2000: p. 2). The diagnosis of the authors of the Plan was that the NHS lacked national standards, that staff groups were inflexible and lacked incentives, that patients were not involved and that there was too much central control. The Plan laid out ten "Core Principles", promising universal and comprehensive service based around the needs and preferences of patients. It promised investment and reform through new staff, new facilities and improved performance. These plans broadly aligned with the feedback from the public, which unsurprisingly called for more and better services.

While the promises of a patient-centred NHS showed a continuation of the shift from the market orientation begun in the previous government, it oddly retained the commitment to consumerist notions of patient or public involvement, focusing on value for money, and hospital waiting lists rather than improvements in the primary care services that most people use. This approach is exemplified by a passage from the Plan:

"Today, successful services thrive on their ability to respond to the individual needs of their customers. We live in a consumer age. Services have to be tailor-made, not mass produced, geared to the needs of users, not the convenience of producers"

(Department of Health, 2000:p. 26)

This passage could be from a similar document from the early nineties, but the approach was at odds with other policies which were beginning to change the organisation and delivery of health services. Health Action Zones (HAZ), Sure Start and neighbourhood renewal were all focusing on health related issues, but adopting an approach that built local involvement into the structure of the partnership, a collectivist approach rather than consumerist. In Plymouth for example, the HAZ's steering and task groups included a majority of service users, (Plymouth HAZ, 2001) while the Sure Start partnership in Hartcliffe, Bristol, also with a majority of parent representatives, actually employed four health visitors to work with local families (A. Dutton, personal communication).

The NHS Plan also stood out as purely focused on the health service, again a contrast with other policies introduced at about the same time which drew attention to issues like social exclusion which cut across departmental remits and which like the HAZ, Sure Start and neighbourhood renewal were blurring the boundaries between agencies and departments. What the Plan did suggest was that more flexibility in organisational arrangements would be beneficial and that health and social care organisations could be brought together.

In January, 2001, Alan Milburn, the Secretary of State for Health spoke of a new relationship between the doctor and patient at the root of the reforms. This would mean a shift in power from the doctor to the patient from a hierarchical relationship to a partnership of equals, based on shared knowledge (Milburn, 2001). To help bring this about lay

representation on professional regulatory bodies and on the NHS Agencies was proposed. What the plan proposed for public involvement was to improve the representation of local communities in decision-making structures and to develop ways for the patient's voice to be heard. This would include improving the resolution of complaints through a Patient Advocacy and Liaison Service (PALS) in each Trust, regular surveys of patient opinion, new patients forums in all NHS and Primary Care Trusts with representation at Board level, an independent local advisory forum in each health authority area and the a duty of scrutiny of NHS organisations on local government, with the power to refer planned change to the Secretary of State.

The Kennedy Report

Follow-up guidance about how or when the proposed system would be implemented was slow in coming, but finally in September 2001, the Department published a discussion document "Involving Patients and the Public in Healthcare", which referenced not only the NHS Plan, but also the Kennedy Report on the deaths of children at the Bristol Royal Infirmary following cardiac surgery. Kennedy's wide ranging Inquiry had not only reported on the failures of individuals in the specific cases concerned, but had also considered how the health care system had functioned and how it had contributed to the deaths. His report had concluded that *"The public are entitled to expect that means exist for them to become involved in the planning, organisation and delivery of healthcare"* (Kennedy, 2001: p. 400) and also that public empowerment means:

> *"a public that is sufficiently informed as to be able to formulate meaningful views about the quality and direction in the planning and delivery of health care; which views are listened to and acted on by commissioners and providers of health care at the core of their decision-making"* (Kennedy, 2001: p. 400)

The report went on to criticise the tokenism of the public involvement that had taken place in the past and the attitude of health care professionals towards it as *"not to be taken seriously and at worst troublesome"*. (p. 401) He called for a change in culture and a shift of power. For Kennedy, the public were not consumers, *"...but citizens* (who) *'own' the NHS"* (p. 402), but as citizens they were needed the opportunity to question and challenge professionals directly.

Kennedy called for development of public involvement around four areas: the planning and development of services, operation of services, assessing the quality of professional staff and in protecting the vulnerable through participation in the management of services. This represented a significantly increased role, in which the public could be directly involved in the management of services, if the proposals were implemented.

The Government quickly signed up to all of Kennedy's recommendations, but as the report observed, there was both a poor record and a sense of frustration with existing mechanisms. The report concluded that

> *"it is of crucial importance that the central goal is kept in sight: that of embedding the involvement of the public in the mainstream...the involvement of the public must not be some side show...but part of the way all NHS organisations work"* (p. 408)

None of Kennedy's conclusions were really new, many were echoes of the NHS Plan itself, and indeed of government documents going back to "Local Voices" in 1992 but what was different was that he called for the embedding of the public voice into all aspects of the NHS, not just planning, not just service delivery, but throughout the health service and all of its organisations.

Involving Patients and the Public in Healthcare

When their own discussion document was published shortly after the Kennedy Report, it began by committing the government to the principles that Kennedy had outlined. The proposals were based on those in the NHS Plan, specifically the development of Patient Advocacy and Liaison Services and Patients Forums in each Trust. However there was a new proposal for a new statutory body called "Voice" to facilitate and strengthen the public's voice at local and national level. A Commission for Patient and Public Involvement in Health (CPPIH) was the national "Voice" which would oversee the arrangements. As with the NHS Plan, the new structures would replace CHCs.

Between the publication of the NHS Plan and this document, the NHS had undertaken another structural change in which health authorities would be superseded by Primary Care Trusts who would commission hospital services as well as providing primary and community services. The NHS and Social Care Act (2001) had also enshrined the duty to "involve and consult" in statute for all NHS organisations.

The period of discussion which followed tended to focus on a number of problems with the proposals. Whereas Kennedy had insisted on embedding public involvement throughout the NHS, the proposals appeared to take it out of the mainstream and into a backwater of a national agency and local organisation, not unlike the CHC. Patient Forums looked unsupported, without definite links to either local or national organisations and with one for every Trust, there were questions of who would sit on them. Responding to the discussion, the Department revised their proposals significantly. The "Advocacy" in PALS was rebadged "Advice", thus retaining the nice acronym, but reflecting their likely role. The idea of a local "Voice" organisation was replaced by a local "network" under the guidance of the national Commission, which would

also support and coordinate Patients Forums and would commission independent advocacy services to support complainants. Patients Forums themselves would have representatives on Trust Boards, but PCT Forums would also have links to other partnerships in their area. The local government scrutiny role was retained.

While this was happening in the mainstream of the health service, across government, there was far more significant change aimed at modernising all public services and revitalising democracy (Barnes et al, 2004). In some parts of the health service, particularly where multi-agency partnerships were a feature of provision, including the Health Action Zones and in Sure Start areas, development of involvement by local communities had gone far beyond what had been envisaged for either primary care organisations or the hospitals (Plymouth HAZ, 2001).

Assessing progress since 1997

The Blair government had clearly broken away from consumerist approach, despite the words of the NHS Plan, relying on legislation, rather than notions of business sense to guarantee the public a role in health service decisions. Whether their concentration on structures of public involvement outside of mainstream NHS organisations could lead to the kind of cultural or power shift that Kennedy and indeed Alan Milburn had called for, it remains too early to say.

The influence of the Third Way on the Blair Government may be more marked outside the health service, but there are areas where the idea of cross-cutting agendas has impinged on health services. The development of Health Action Zones, Sure Start and the issue of social exclusion have been specifically targeted to areas of the greatest inequalities in health, bringing resources into health improvement activities and often adopting an empowerment or community development approach to service

provision (Ewles et al, 2001; Fisher et al, 1999; O'Keefe & Hogg, 1999). Policies like these and neighbourhood renewal have taken a lead in involving local communities in locally based decisions (Matka et al, 2002; Crawshaw et al, 2003; Department of Health & Neighbourhood Renewal Unit, 2002). So whereas health service managers in general struggled to come to terms with public involvement (Florin & Anderson, 2002; Rowe & Shepherd, 2002), an existing model appeared to be available, but it was a model which had developed not from consumerist roots, or indeed from a quest for legitimacy in decision-making. The basis of this approach was usually seen as empowerment or health development and its roots are in health promotion and community development.

2. 4 Implications for the Research

The focus of this research is on contemporary practice in public involvement. The shifts in health policy over the past few years, especially the structural changes in public involvement have made it difficult to pin down, but although there may be structural changes, the underlying issues of the relationships between the public, service users, health service managers, professionals and the government remain at the heart of the research.

The expressions of the understandings of these relationships have changed since 1997 as the rhetoric of the market, dominant early in the nineties has been superseded by that based on notions of partnership. For the research, this meant a reorientation. Whereas distinctions between a market orientation and health development appear quite clear, the partnership agenda appears to embrace that of the empowerment of local people in their relationship with decision-makers. This shift in the orientation of policy brings more to the fore the deeper motivations of health service managers. Unlike the consumerism promoted by Griffiths, where the manager's role was to interpret needs and respond to the

consumer (to "champion" the people), the partnership model calls for a sharing of decision-making. The development of the partnership agenda, the emergence of cross-cutting policy issues and new sources of funding like the New Opportunities Fund (NOF) have altered the landscape in the health service and across public services, bringing more radical approaches that emphasise local roles in decision-making to the delivery of health services. There may be consequences for this research from these changes.

There are questions to be asked about whether there has been significant progress since Local Voices, or indeed since the election of the Blair Government in the mainstream of the health service. And there are issues of the extent to which national policy has changed practice at a local level. The challenge of Local Voices was for a radically different approach, this was echoed and amplified by the Kennedy Report. The final issue for my research is: is this challenge still unmet?

Chapter 3: Understanding Public Involvement

3.0 Introduction

Over the last twenty years, it is evident that there has been a transformation in the relationship between the individual and the health service. Klein calls the public *"ghosts in the NHS machinery"* (Klein, 1989: p. 77), while Lupton and colleagues note a significant shift in the relationship between this public service and the public from "patient" to the more active "consumer". The relationship remains essentially individualistic, with little *'...determination to enhance the responsiveness of the service to the collective views of local communities and the wider public'* (Lupton et al, 1998: p. ix). This is despite public involvement in NHS decision-making becoming a recurrent theme of policy documents since the 1980s, (Department of Health, 1990; Department of Health, 1999; NHS Executive, 1994; NHS Executive, 1995; NHS Executive, 1996; NHS Management Executive, 1992).

Lupton's recognition of the shift from patient to consumer (and more recently to "partner"), despite her reservations has been accompanied by the emergence of central policy and local activity and an explosion in published material and academic interest in the subject.

Following on from the detail of policy developments examined in Chapter 2, I will examine some of the theoretical context for involvement in public sector decision-making. The Chapter begins with a discussion of alternative models for understanding public involvement in decision-making in the health service and in similar contexts. These provide a framework within which to develop the research questions and offer insights into the relevant theoretical perspectives that will inform the research. I will go on to discuss the critical issues that appear to underpin the development of public involvement at this stage in the health service. I

will also argue that there are factors that act to restrain the development. The balance and interaction between these drivers and restraints and what lies behind them is crucial to the research.

3.1 A conceptual framework

Participation, involvement and consultation are contested terms which are used more or less interchangeably in many discussions of patient and public participation in decision making in health. I will tend to use participation and involvement interchangeably, but reserve the term consultation for specific meanings concerned with statutory requirements that allow comment to be made to agencies. Consultation is initiated and controlled by the agency and fits into its planning decision-making structure. Participation and involvement on the other hand are more malleable terms and have looser meanings.

Participation is variously defined by the UN Human Development Programme as *"...constant access to decision-making and power"*, (United Nations Development Programme, 1993: p.21) and by the Institute for Housing Tenant Participation Advisory Service as *"...views...requested in order to consider them before decisions are made"*. (Institute of Housing & Tenant Participation Advisory Service, 1994: p. 3)

These definitions are perhaps best understood when seen as different points on a scale of all participation. The assessment of participation in decision-making processes owes much to the "ladder" concept attributed to Arnstein (1969). This and similar models identify a hierarchy in which at the higher levels, control increasingly resides with participants or the public rather than the state or providers of services.

The original Arnstein model (see figure 3.1) shows a progression from manipulation to citizen control (Harrison & Wistow, 1992). It would be

possible to situate the above definitions of participation on the ladder, with the Institute for Housing Tenant Participation Advisory Service appearing at a lower level than the UN Development Programme. Burns et al (1994) and others (Hickey & Kipping, 1998; Martin & Boaz, 2000) have offered developments of this model, but in general it is criticised as depicting the relationship between the individual and public services as a dualistic struggle in which progress is indicated by change towards citizen control (Richardson, 1987). As Contandriopoulos (2004) has pointed out, this may not always be the case, however that does not mean that changes within the ladder, for example a shift from "manipulation" to "informing" will not always represent a progressive shift.

Figure 3.1: Arnstein's Ladder of Participation

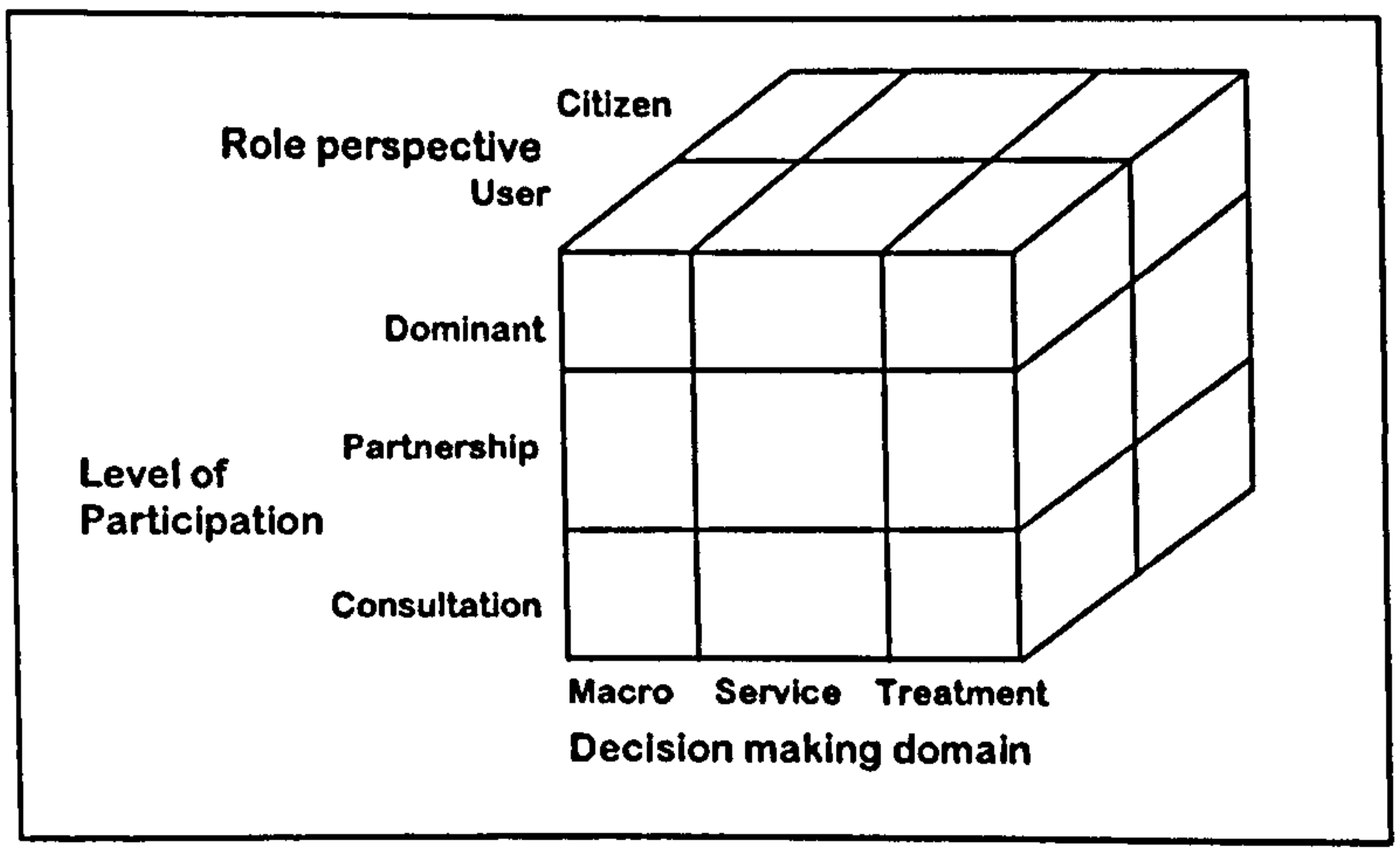
Citizen Control Delegated Power Partnership	Degrees of citizen power	Full participation
Placation Consultation Informing	Degrees of tokenism	Partial participation
Therapy Manipulation	Degrees of control by others	Non-participation

Martin and Boaz (2000) and Hickey and Kipping (1998) redefine the ladder as a continuum and concentrate on partial and full participation, suggesting a link between lower levels such as "informing" and consumerism, while citizen control translates into democratisation. In drawing these comparisons, they hint at important external factors that play a part in determining the level to which programmes or instances of involvement can aspire.

A development of the ladder approach is offered by Charles and DeMaio (1993) who extend it into three dimensions, first by recognising the

distinction between the "user" and the "citizen" and second by introducing the notion of context in decision making. The user-citizen distinction is an important one as the user's focus is narrowly defined by their involvement with services. On the other hand, the citizen has a broad interest covering all services and the balance between them. The third dimension is the decision-making domain. Charles and DeMaio identify three domains, the "treatment" level which corresponds to individual involvement in decision-making, and two collective levels, the "service" level and a "macro" or system level. So within the Charles & DeMaio model, decisions can be located in a three dimensional space, according to which "public" is involved, what level of involvement there is and what is the domain of the decision (see figure 3.2). The strength of this model is that it relaxes the value judgement that a consumer or citizen's dominant position is "better", while it also offers a more complex and realistic model of decisions. The distinction between the service user and the citizen is particularly important in that user's experience of services and personal relationship with them gives them a deeper insight into the services they use.

Figure 3.2: Charles and DeMaio's Framework of Participation



On the other hand the service user's view will be less informed where decisions are taken about other services, while they may be unbalanced in

decisions about the allocation of resources between services. Unlike Arnstein, Charles and DeMaio concentrate on higher levels of involvement, omitting what Arnstein calls "non-participation". Perhaps the weakness of this model is that while enabling the categorisation of involvement activities, it does little to add to the understanding of how or why involvement might occur or of the forces driving or restraining the development.

Whether the three dimensions of Charles and DeMaio's model are comprehensive is open to question. A further distinction is made by Richardson & Bray (1987), and later by Harrison et al (2000) who distinguish forms of involvement where participation in decision-making is direct, that is where the participant has an active part in the decision-making forum, as distinct from those that are indirect or passive and mediated by others, often professionals. In indirect approaches, the views of participants are often aggregated or summarised for use by decision makers. The justification for this approach may be that it increases input into decision-making without the need to revise the process, however such forms of involvement may be used by health services to regulate the level of participation in decisions (Harrison & Mort,1998). Although this is most obvious where the form is indirect and participants take no part in the decision-making forum, it is also possible in direct involvement, where through more subtle means like the manipulation of the rules and conventions of participation, effective involvement is compromised.

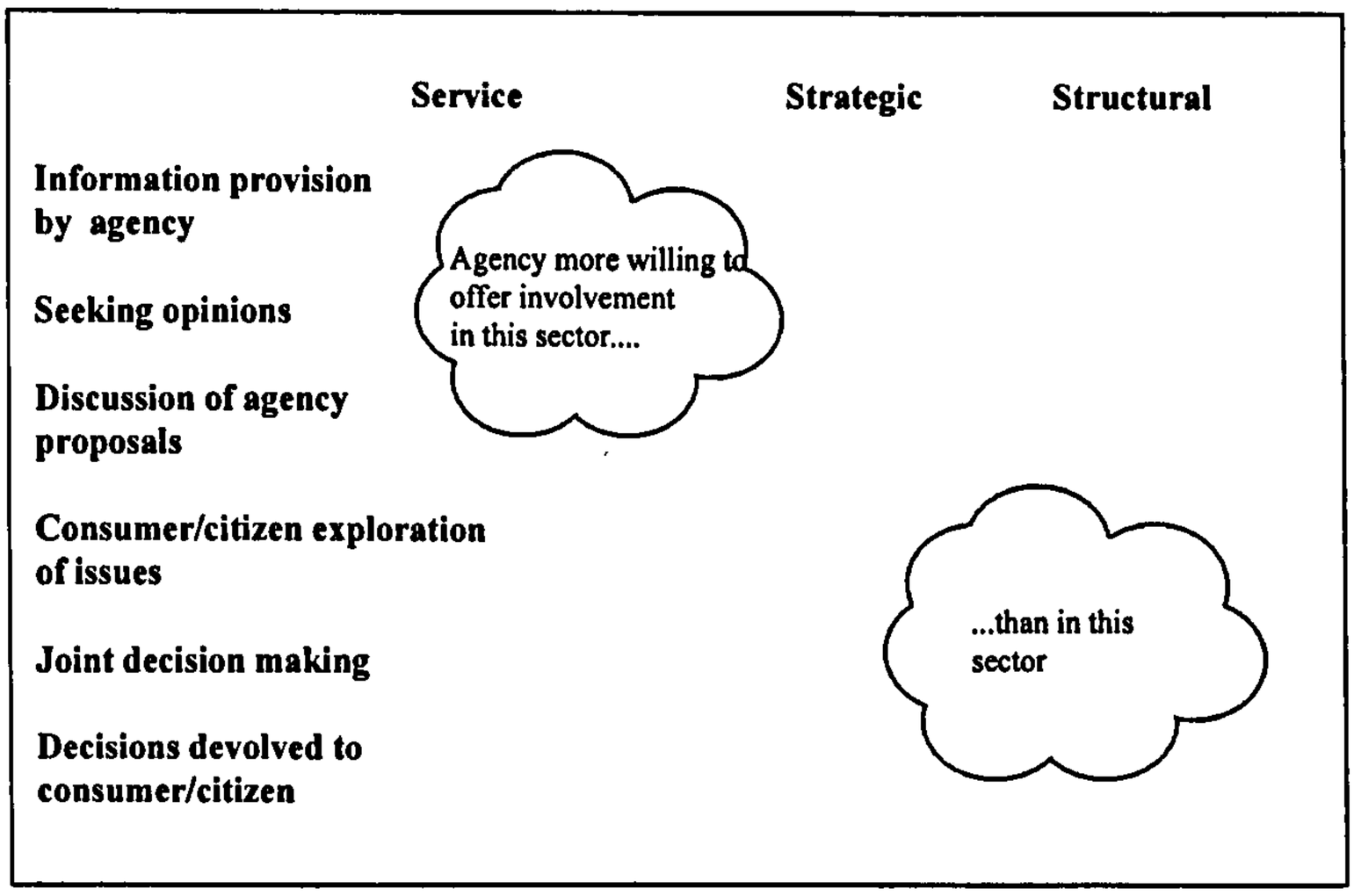
Skelcher's work (1993) still drawing on the Arnstein approach also concentrates on the domain of decision-making and identifies the importance of the role of institutions in regulating participation. According to Skelcher (figure 3.3), there can be a differential willingness to accept participation on the part of the state or professionals. Some decisions are seen as appropriate for involvement, while others are not. Implicit in the

model is overall control by the state or other institutions of the process of decision-making.

Using a two dimensional space, Skelcher explains differences in the potential for involvement with reference to domains within which decisions are made. A similar point is made by Barnes (1999) who sees professionals as threatened by involvement. They may regard themselves as legitimately providing input on behalf of patients or clients and may view the process of involvement as complicating already difficult decisions. It is more likely that participation will be permitted in decisions that are seen as representing no challenge to the status quo than those that challenge prevailing hierarchies.

Skelcher's approach really gets to the heart of the debate by highlighting the underlying tension between the drive for new approaches to citizenship and democracy and the entrenched power structures and ways of working in society. Applying this model to health, we can envisage the horizontal axis as indicating degrees of challenge to entrenched state or medical power, in which participation in decisions about peripheral issues like the decoration of the waiting room is uncontroversial and may be welcomed by professionals. Change within the location of services or even the shape of services may still be permitted, but debates about the structure of the system or the model of health are not open for debate and not entered into by professionals. By opening the model to external influences, to the context within which the decisions take place, Skelcher moves the debate beyond the implicit pluralistic assumptions of other models, we can now understand that participation is not a neutral process but has an emancipatory dimension.

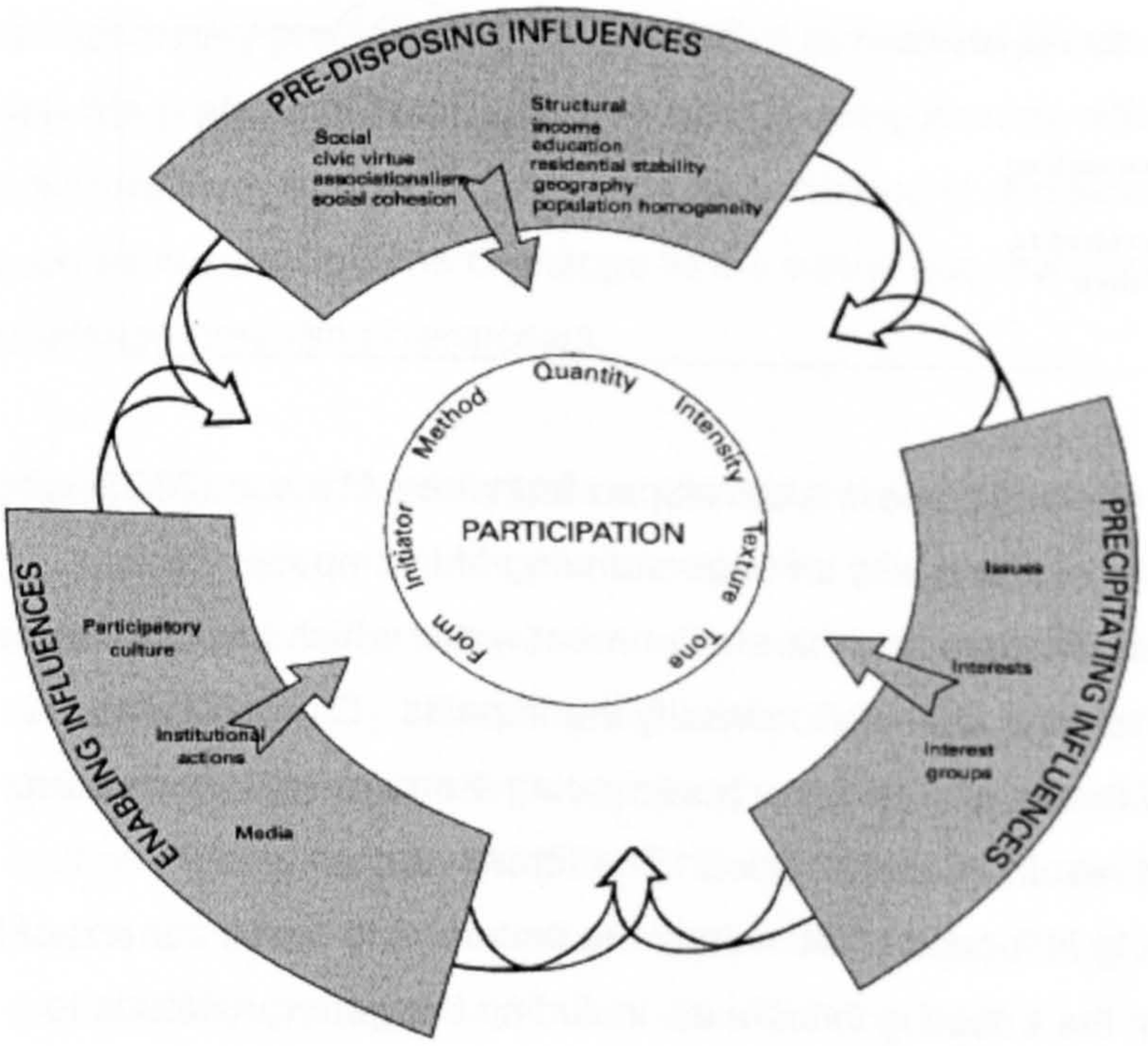
Figure 3.3: Skelcher's model of public involvement



The discussion of context is developed further by Abelson (2001) who offers a model that seeks an understanding of the inputs into the involvement process and the environment within which involvement takes place, rather than seeking to classify the impacts. She recognises a number of forces at play in the participation arena shaping the nature, extent and results of participation. The forces are grouped into *predisposing influences* that include the cultural and social context of the population, the *enabling influences*, including the general attitude to participation, the institutional context, those actions taken by local institutions to encourage involvement and media actions and reactions. The third group of forces are *precipitating influences*, the events and actions that lead to the initiation of involvement. Although not articulated in the model, there is scope for the influences to be positive or negative and promote or obstruct participation. For example, enabling influences are balanced by disabling influences, such as lack of openness and the vested interests of existing hierarchies. McKie (2003) categorises barriers to participation into three groups, social barriers including lack of knowledge and skills which may result in consistently deferring to the criteria and agendas proposed by statutory agencies; structural barriers

that lead to closed processes, disconnection of public discourses from decision-making and prevent the true voice of citizens and service users from being heard; and administrative barriers which relate to the reluctance to adapt decision-making to the needs of potential participants and serve to exclude citizens or restrict their role.

Figure 3.4 Abelson's framework for analysing participation



Unlike the other models presented, Abelson, together with McKie's contribution, gives us a way to interpret public involvement, rather than assess it. The framework appears flexible enough to be used to analyse an individual decision or a programme of involvement, but will not, on its own, provide an assessment of "success". Abelson aims at an understanding of the forces at play rather than means to measure the influence of local opinion.

These models all provide insights into the process of involvement. At the basic level, Arnstein's ladder provides a simple scale on which to assess involvement processes. Charles & De Maio also provide a basic scale on which to measure involvement, without a mechanism for understanding the process or the forces involved. Skelcher hints more at the complexity and other forces at play, while Abelson provides a framework for a more comprehensive analysis.

While all can contribute to assessments and understanding of programmes of involvement, none provides an ideal analytical framework. This research takes elements from each model in an attempt to develop a multi-dimensional model of public involvement. Arnstein still provides the most appropriate levels of participation, principally because her ladder includes non-participation. From Charles & DeMaio, the role distinction between the citizen and the use is an important contribution. However to see this as a duality is restricting as in some contexts participants may be users, in others citizens and secondly, participants who have caring responsibilities may not fit comfortably into either category. In the third dimension, the decision-making domain, the categorisation used by Skelcher into "service", "strategic" and "structural" domains is helpful in extending consideration to underlying issues that may not be directly tackled by decision-making forums, but are fundamental nonetheless to decision-making. Lastly, a fourth dimension, of form as suggested by Harrison et al and Richardson is justified. Direct involvement implies a role in decision-making that goes beyond the provision of views and/or information. It implies a voice in decision-making forums and it is only when this is available that it is possible to aspire to the higher levels of Arnstein's ladder.

Abelson's model looks at the inputs into involvement and contributes to the understanding of the context within which involvement takes place, although negative influences need also to be considered. By focusing

more widely on the other phenomena related to involvement, it assists in relating real world examples to the framework.

3.2 Why has public involvement in health service decisions grown significantly in recent decades?

Speaking at the launch of the Commission for Patient and Public Involvement in Health in 2004, Sharon Grant, the Commission Chair was quoted as saying:

> *"The survival of the NHS depends on involving the patients and public. If the NHS fails to establish a new dialogue it will lose their confidence and support, and they are the ones who pay and vote for it [to exist]."* (quoted in Gould, 2004: p 424)

So in her view, the case for public involvement in health service decisions rests on the premise that in a democratic society, public services should be accountable to the public and that improving the health of populations and delivering better services relies on understanding the needs, views and values of those who use them. Harrison (1997) calls this the "logic of democracy".

For others, the case for public involvement is more concerned with assuring the quality of health care (Crawford et al, 2002) by making the way that services work responsive to service user needs. While other research suggests that participation in society's decision-making structures itself confers health benefits (Wallerstein, 1992; Bosma et al, 1997)

On the other hand those who doubt the importance of public involvement refer to the need for services to be planned on the basis of evidence and the potential for an allocation of resources that disadvantages minorities (Doyal, 1997; Ham 1998). Contandriopoulos (2004) argues that participation is only one alternative approach that would enhance

democratic accountability. He contends that involvement takes place in a specific social and political context and cannot be separated from it. Public participation is not a simple two-way transaction between statutory authorities and the public, but requires additional inputs including advocacy and mediation in order to be effective. This is a similar view to Abelson's, that involvement is an outcome of certain conditions in society that encourage or discourage participation (Abelson 2002). Underpinning this perspective is the assumption that the process of health service decision-making is technically complex and participants require certain assistance, knowledge or experience to participate. Some writers, while not questioning its desirability question the practicality of public involvement, and express doubt that involvement will result in more democratic accountability as longstanding professional and managerial interests will resist a shift in decision-making power (Dixon & Florin, 2004).

The growth of public involvement as a policy issue can be accounted for in a number of ways, but it arises out of other broad policy themes and global trends that have influenced the NHS in recent years. For Conservative governments in the 1980s and 1990s, it was viewed as part of a move towards public services delivered through market or quasi-market mechanisms. In this context, service users are constructed as consumers of services with demands that providers must respond to.

Since the 1997 election, New Labour have tended to emphasise the development of a new relationship between the state and the citizen that is neither the bureaucratic paternalism of the seventies, nor the marketism of the eighties and nineties. The "Third Way" emphasises partnerships as a way of delivering services to local communities, with patients and citizens along side statutory and voluntary sectors as members of these partnerships (Giddens, 1997).

I contend that three key forces have played major parts as predisposing, precipitating and enabling or disabling influences (Abelson, 2002) on the development of public participation in health decision-making: the desire to develop local accountability in response to a growing concern about the transparency of decision-making in public services; a renewed interest in citizenship and the state of the democracy in this country that is perceived as dysfunctional and outdated; and issues of power in society and particularly the power of professionals in the health policy field. In the remainder of this chapter, I will explore these influences, establishing what their implications might be for public involvement in the NHS and this research in particular.

3.3 Accountability

The beginning of the NHS in 1948 transformed the relationship between the public and health services from one based on market forces or charity to one based around the rights of citizens. (Lupton et al, 1998) Like Harry Truman's "the buck stops here", Bevan's "bedpan" view of accountability was an expression of the unity of the NHS; the sound of a bedpan falling on the hospital floor anywhere in the country would resound around the Palace of Westminster and the Secretary of State bore responsibility for all bedpan activity and everything else that happened in the NHS. Through its first decades, the public's relationship with the health service on a policy level was short term and related only to electoral politics, so that the consequence of crashing bedpans would be felt only through the ballot box (Corrigan & Joyce, 1997).

Recent research by MORI (Duffy et al, 2003) found that people are less likely to accept the advice of experts uncritically and that trust in institutions has declined over recent years. Trust and accountability are linked and there is a perception that when challenged, institutions will cover up and close ranks, rather than admit fault. Stewart (1992) refers to

accountability as two sided, giving account and being held to account. Oliver's definition similarly identifies a two fold nature,

> *"a framework for the exercise of state power in a liberal-democratic system within which public bodies are forced to seek to promote the public interest and compelled to justify their actions in those terms or in other constitutionally acceptable terms (justice, humanity, equity); to modify policies if they should turn out not to have been well conceived; and to make amends if mistakes and errors of judgement have been made. "*(1991:p. 28)

Sullivan considers the need to control the actions of the state and to seek redress as the most important functions of accountability processes (Sullivan, 2003). How control occurs is the subject of the debate. Accountability is a concept that is embedded within theoretical perspectives. The neo-liberal interpretation of accountability which was the dominant understanding for the Conservative governments of the 1980s and 1990s was market based, relying, at least theoretically on economic forces to generate accountability within market-like structures (Waldegrave, 1993). Market models focus attention on service users as consumers, with choices and the power to control the market.

Other approaches to accountability call upon public officials to meet standards of performance or submit to "expert" scrutiny, but the current government has also emphasised a "third way": the development of shared decision-making in partnerships as a way to guarantee local accountability (Giddens, 1997). This approach introduces new levels of complexity as multiple partners from public, private and voluntary sectors may work together to provide services without clear hierarchies or well defined roles. Sullivan (2003) refers to this as the problem of "many hands". The partnership approach offers opportunities for the active participation of public and service users as both producers and consumers of public services.

Markets and consumers of health care

The restructuring of welfare services, which has taken place in most western democracies in the last twenty years was largely begun in the name of consumerism (Clark & Newman, 1997). The influence of private sector management theories advocating consumer centredness (Peters and Waterman, 1982) became strong in the 1980s as public sector organisations turned to more "business-like" operations. In the health service, professional paternalism was challenged by the marketised vision of the health service that began to be presented by the government in the late 1980s. The "consumer" is an informed figure, acting in the market with the aim of seeking satisfaction of his/her demands. In contrast, professionally led services rely on specialised knowledge and expertise being employed to define the needs or diagnosis of the passive "patient". (Clarke & Newman, 1997 p114)

The consumer is also an individual, but since the 1960s, there has been a dramatic expansion in the number of non-statutory groups of, or for, users of health and social services who have, to an extent developed knowledge bases that have challenged the professional paternalist model by popularising expert knowledge. In recent years, this has been aided by increased access to information, particularly over the internet (Zeibland et al, 2004). The College of Health now lists at least 2,500 groups concerned with health and social care (Sang, 1998). This growth is attributed by some to an increased dissatisfaction with the process of health services and a concern to influence decision-making in the NHS (Lupton et al, 1998), but may have its roots in the transformation of society away from mass production and politics towards more specialised, networked forms (Considine, 1999).

Conservative Governments in the 1980s and 1990s identified with the new right public choice theories (Rowe, 1999), an approach which tends to see

accountability in the public sector mirroring the private sector market accountability to the customer. This represents a shift from the political to the economic (Saltman, 1994). The tendency for bureaucracies to expand public services and to concentrate on maintenance or expansion of the bureaucracy, rather than quality of services is fundamental to this view (Niskanen, 1971). Democratic control is seen as insufficient, but it is argued that the market can introduce the required discipline (Waldegrave, 1993). Taxpayers are seen as the shareholders of the public services, while the service users are viewed as consumers (Rowe, 1999, Waldegrave 1993). In this model, giving account to the taxpayer is only about demonstrating the efficiency of the enterprise, while giving account to the consumer is about providing for needs and standards of service.

In the marketplace, service providers are forced to develop more responsiveness and greater accountability. The economic mechanism of "exit" generates accountability as consumer-citizens who are not satisfied will exit to an alternative provider. The possibility of exit pressurises the provider to find out what is at the roots of the dissatisfaction. The decision to exit has costs, for example it might mean travelling further, accepting a service at a higher price or foregoing quality. So the business that can raise the "price of exit" will be more successful in keeping customers.

Where choice is limited, as it may well be in any health service market, but particularly in the NHS, the price of exit is high. For the customer there is an alternative mechanism for expressing dissatisfaction, "voice", through which he can invoke procedures to pursue satisfaction such as complaints. Making the "voice" option more attractive by responding to complaints, and listening to customers needs for example effectively raises the price of exit and develops loyalty, retaining the customers who would otherwise seek opportunities to exit. (Hirschmann, 1970) What the economic view does not include however is the possibility that where "exit" is not an option, the consumer will only employ voice if they do not feel

powerless in the face of bureaucracy and entrenched interests. (Rowe & DeVanney, 2003)

While their background philosophy emphasised the power of the market, the reality was of a publicly provided health service without an effective "exit" or an established tradition of listening to the voice of patients. The Conservatives saw the importance of developing other forms of consumer pressure, including the "voice" mechanism. Service user views could be utilised to generate a move to higher levels of service quality. Initiatives like the Patient's Charter were idealised as part of the drive to raise standards (Lupton et al, 1998), but led to managers setting standards for services without reference to patients. Achieving standards then becomes a performance target for managers, rather than a measure of service quality.

But consumerist change has not only been heralded by the new right, it has been deployed in critiques of the bureaucratic paternalism of public service from both left and right of politics. While the right has emphasised the market, the left has focused on what are termed public sector notions of consumerism in the decentralisation of services and the empowerment of service users (Croft & Beresford 1990), public sector notions of consumerism also embrace citizenship and propose a radical shift in the distribution of power (Croft & Beresford, 1990; Potter, 1988). However consumerism is limited, individually focused and deals with the details and the mode of delivery, rather than identifying the appropriate services. It is also an inadequate form of expression for the range of relationships between the public and welfare organisations (Klein & Millar, 1995; Potter, 1988).

The emergence of consumer groups, while assisted by the growth of consumerism and regulatory arrangements like joint planning began before being encouraged by the legislative framework, (Mort et al, 1996)

so while government may have added to the dynamism of this growth, arguably it was initiated by service users themselves. Writing about the mental health field, Anthony and Crawford declare that

> *"there can be little doubt that the momentum for a 'consumerist ethos' has been facilitated by service users themselves, with charities such as MIND and the National Schizophrenia Fellowship generating a powerful influence on policy and service development"* (Anthony & Crawford, 2000: 427)

Social movements

The momentum referred to by Anthony & Crawford (2000) may be labelled by them as consumerist in nature, but like Croft and Beresford (1990), their subject is much more than a process for responding to consumers and may have more in common with the social movements concerned with class struggle and identity than consumption. However where class aligned social movements were mass organisations, new social movements are associated with the fragmentation of society along lines of identity constructed in many dimensions including gender, disability and sexuality. Class conflict has less relevance to modern society than to earlier eras, but new movements have emerged based on more recently acknowledged areas of struggle, including civil and human rights (Scambler & Martin, 2001).

Habermas' view was that new social movements occupy the *"seam between the system and the lifeworld"* (Habermas, 1981 p.36) that is where the institutions of the economy and the state impinge upon everyday life. It is where the lifeworld and the system meet, Habermas argues that new social movements *"form the raw materials of the public sphere" (*Edwards, 2004: p113) as they raise issues of their own identity, they simultaneously engage in struggles with the state over its legitimacy and accountability.

The central conflicts of modern capitalism surround these discourses of identity, accountability and legitimacy, rather than earlier economic struggles. The growth of bureaucracy, regulation and the increasing organisation of everyday realms of action represents the extension of the "system" into the lifeworld. This provides the material for new conflicts and tensions which contribute to the revitalisation of the "public sphere" by actors who seek to defend traditional lifestyles or institute new ones on their own terms and question the legitimacy and accountability of the system (Habermas, 1981; Edwards, 2004).

Offe (1985) identified characteristics of new social movements as open and participatory in organisation and with a high degree of solidarity among members, while Della Porta and Diani (1998) note shared belief systems as more characteristic than structured organisational forms. Their aims tend to be emancipatory with a focus on challenging predominant politics and belief systems (Brown et al, 2004). Examples from the health field would include mental health survivors, the disability rights movement and AIDS activism although Allsop (2004) and Brown et al (2004) include as new social movements groups who challenge access to health systems, rather than offering a deeper critique of health issues.

Offe and Melucci stress that unlike pre-existing forms of political organisation, the role and politics of such social movements is to extend the scope of the political into new areas of society including the environment, sexual identity and health (Offe, 1985; Melucci, 1985) However, membership or control of groups that pursue the ends of these movements may be overtly restricted to those who share characteristics. For example, disabled people may welcome the support or assistance of non-disabled people, but not allow participation in decision-making.

The relation between emerging notions of community and citizenship that are inherent within new social movements and health service

management is important, as is the response of public managers to the emergence of a more flexible post-bureaucratic society in which it is not possible to distinguish between lifeworld and system in Habermas' terms, not due to colonisation but because structures are much less rigid and may be characterised more as networks rather than traditional organisational forms. The local health service manager may be reflexive and proactive, but not be attuned to the development of the active citizen in user or social movements, which offer more complex challenges to ensure accountability.

People become involved in new social movements because they feel that they are marginalised by dominant social practices. Movements gain adherents because they help in the development of a positive sense of identity. Interaction both helps individuals to find an understanding of their situation and helps to forge a collective identity through the development of a particular discourse and a set of perceptions and ideas on how action should be mobilised (Allsop et al, 2004). They tend to have little trust in the state or its legislative function as a remedy for their complaints, but also doubt the likelihood of revolutionary transformation in society, so set about changing society from within (Crossley, 1999). Social movements are agents of change, seeking to transform the lives of particular groups and transform the perceptions of society in general.

From the perspective of the disability movement, Campbell and Oliver (1996: p.105) write *"...for us, transforming both personal and political consciousness is one of the key factors which separates new social movements from the old..."* By contrast, for groups like the Long Term Medical Conditions Alliance the personal transformation is not linked to political change, through direct challenges to the health system. They prefer to work with providers of care for improved conditions for individuals and develop joint approaches and partnerships (NHS Executive, 1996). Barnes (1999) found that the distinction between identity and interest

groups was clear, with identity groups being deeply linked by a common culture and purpose, experience and language and interest groups having less solidarity and a more transient nature. These distinctions were not adequately appreciated by health service managers.

Mort et al (1996) speculate that there may be the opportunity for the user movement to become an intermediary between the purchaser and provider but that successfully doing so would require a high level of skill and politicisation. In more contemporary terms that may mean becoming involved in formal partnership arrangements, but there is a question whether this achieves the aims of movements who focus on more global goals of liberation and rights, or challenge the assumptions made by the health service about the origins of illness. Social movements face difficult strategic decisions about the balance between the desire to influence policy direction and the need to maintain independence and autonomy (Craig et al, 2004; Wallcraft, 2003), however solidarity and shared belief systems should not be confused with homogeneity and while the participation of service user organisations in partnership arrangements has become commonplace, the issue of whether to become involved remains an area of dispute within service user movements (Wallcraft, 2003).

Accountability and public managers

The emergence of health based social movements and the rise of consumerism can be seen in Abelson's terms as enabling influences for the development of public participation and local accountability, which may contribute to revitalised debates about health issues, But in practical terms, managers in the health service, particularly since the Griffiths reforms (1983) play a central part in the process of policy making. Their role is both as agents of central policy and in guiding or coordinating local policy development. The Griffiths review of management in the NHS and

the 1990 reforms gave more local autonomy to managers in NHS Trusts and health authorities but did so without establishing formal mechanisms of accountability at local level. Indeed, health authorities were at the same time reduced in size by the removal of local authority appointed members. Managerial claims to legitimacy rest on scientific rationality, objectivity and moral neutrality (Jones, 2001), but health service managers rely additionally on establishing local legitimacy for decisions that clearly affect the care and treatment available to local people (Sabin, 1992). Similarly, Jervis and Richards found that public sector managers perceived a "democratic deficit", which they say has forced contested decision-making upwards to government, and devalued local politics and autonomy (Jervis & Richards, 1997).

The relationship between the service and the service user is a crucial part of the "new public management". The term does not necessarily indicate a coherent approach, but Barberis identifies the characteristics of the new public manager as combining the pursuit of delegated powers, efficiency, a strong consumer orientation and performance management (Barberis, 1998). Mulgan (2000) argues that new public management compromises accountability in the public services. Proper accountability is external but new public management has led to the growth of internal processes such as, measuring performance which are falsely characterised as delivering accountability. Much of the inspiration comes from the private sector and tends to emphasise innovation, efficiency and responsiveness, within a very different and internal accountability structure in which responsiveness is a means to an end rather than a goal per se. Harrison and Mort's view is that in the public services, involvement will be used by public managers in the same way: drawn in to buttress particular views when appropriate, but with dissident or unsupportive views regarded as unrepresentative (Harrison & Mort, 1998).

Harrison and Mort (1998) identify a cadre of health service managers whom they term "consultation entrepreneurs" who seek opportunities to build public participation into planning and decision-making structures. North in a study of policy making in two health authorities found that among health service managers in general there was considerable openness to service user views (North, 1998). Milewa et al (1998) argue that these are aspects of the development of what they term "active management" in the health service, concluding that health service management is developing as a distinct profession, in which one role is to develop dialogue with local populations. Both Salter (1998) and Bohman (1998) are equally positive - identifying the democratic component of public involvement as concerned more with accountability and legitimacy than efficiency. There is an inherent tension between legitimacy seeking and efficiency seeking public managers and Ferlie et al (1996) conclude that there are a number of variants of new public management, seeking quite separate aims. They identify four:

- Seeking efficiency though private business methods
- Downsizing and decentralisation
- The search for excellence
- Re-energising the public sector

As Hewison (1999) says, this represents neither a neutral, nor a coherent set of aims but may be indicative of the individual motivations of public managers, including their "micropolitical" activities. Public involvement could conceivably assist in achieving the goals of any of these variants so that the "user" card is an important one for the manager to have up her sleeve, however it is equally likely that public involvement could play no role. Milewa's professional health service manager is concerned with a number of objectives, including responding to public need. North's analysis appears to concur, while Sabin's observation of the legitimacy

seeking health service manager may also argue that the new public manager's skills should incorporate processes of public involvement.

The Third Way: networked accountability

The reforms of the 1980s and 1990s have led to a transformation of the nature of the state and challenged its capacity to develop appropriate accountability mechanisms appropriate to its new role of governance. If the consumerist approach was influential with the Conservative governments in the 1990s, particularly in the early nineties, when the New Labour government was elected in 1997 its avowed project was to modernise and democratise government (Barnes et al, 2004). Among its innovations were principles to guide accountability processes in the new complex environments of public services. These included a commitment to efficient, transparent & accountable local decision making; to responsiveness to local citizens & communities; to local leadership and to securing local well-being through a collective effort (Sullivan, 2003).

New Labour's approach was inspired by the "third way" approach to social democracy developed in this country by Giddens (1997) and elsewhere by Beck (1992) and Etzioni (1995; 1999) which acknowledge that both rights and responsibilities are conferred by citizenship. The nature of the new approach to public services was to propose partnerships to take forward the modernisation project. Partnership has become a feature of the discourse of local governance and central to the modernisation agenda. Giddens (1997; 1999) sees partnership as part of the new relationship between the state and the public, a feature of the third way and central to the "democratisation of democracy". As a result, even more complex structures have developed and what has become necessary is a framework for accountability that can work with the 'many hands' now involved in governance.

Such approaches are seen by Papadopoulos (2000) as linked to the fragmentation of society along many different dimensions, including class, race, gender, religion and sexuality. This is typical of late modernity and communitarian or third way approaches seek to manage fragmentation by harnessing multiple identity groups into processes of governance. However, new social movements as described may well resist this. Governance can be seen as a method of social coordination which does not presuppose the autonomy, still less the sovereignty of a public governor but consists of the interaction of a plurality of "governing" actors who are not all state or even public actors (Papadopoulos 2000). The notion of governance has emerged over the least two decades through the transformation of government and as a technology for the resolution of conflicts. In this perspective, it represents a communicative dimension involving civil society imposed on the strategic dimension of political activity. This accords with the Habermasian view which argues for a deliberative form of democracy based on broad popular participation (Jones, 2001). Planning and policy making are transformed in this scenario from a technical into a facilitative activity, the management of partnership working within a complexity of organisations has the effect of blurring distinctions between them. There are important implications for attempts to increase public involvement in decision-making within state institutions like the NHS. However matters of considerable concern are structural and cultural factors that constrain the ability of individuals to participate, including asymmetries of power (Jones, 2001). In formal partnerships arrangements, Atkinson (1999) sees the reproduction of existing hierarchies as the powerful organisations determine the rules and conventions and legitimate the contributions of partners (Clegg, 1989)

Partnerships are organisational forms that are constituted by more or less formal linkage between existing organisations for the purpose of addressing what are perceived as common goals. In some instances, for example in establishing Local Strategic Partnerships (DETR, 2001), there

is a mandatory development, forcing organisations together to achieve "joined-up" government. At other times, such as in the development of neighbourhood renewal, more formal partnerships have been accompanied by less formal arrangements that have brought together people from different organisations to achieve change.

In order to have an impact in decision-making forums, service users and citizens may have to adopt the institutional language and way of thinking, what Atkinson (1999) calls the "mode of rationality". Social movements, who may appear natural partners in "third way" partnerships will resist attempts to incorporate them into the public sector's mode of rationality, while local residents may well be reluctant to participate in meetings conducted in unfamiliar language and held at inconvenient times. What the New Labour modernisation agenda has done is to promote a new complex model within which public participation in decision-making can contribute to overall governance. Arguably, it lays Waldegrave's (1993) insistence on the precedence of market-led accountability to rest, but there remains a question of whether citizens are able to participate equally within these kind of arrangements.

3.4 Citizenship and Democracy

The conventional model of citizenship derives from Marshall (1950) and centres on both formal membership of a state and a series of substantive rights, including civil, political and social rights. The Marshallian model is widely criticised for promoting a particular and passive view of citizenship (Prior et al, 1995; Lister 1997), which has been used by the right as a means to exclude minorities (or majorities) from the benefits of society, but it has provided a valuable mobilising tool for social movements which have focused on the denial of rights in battles for emancipation. Prior and colleagues relate citizenship to both status and action (Prior et al, 1995). The status of citizenship comes from membership of political community

which brings with it the associated rights to vote, protection under the law and social rights such as health care and education. The citizen is required to do little, but taking the opportunity for participation in decision-making can be seen as fulfilling the potential of the status.

The roots of citizenship are in political traditions of liberalism and civic republicanism. Liberalism casts citizenship in terms of status involving the rights granted to individuals, whereas civic republicanism emphasises the responsibilities of the individual to wider society (Lister, 1997; Painter, 2000). Debates over citizenship have traditionally centred on rights, but attention has shifted more recently from passive rights to active participation. Even where rights are formally granted, Caragata (1999) argues that they may be so constructed that marginalised groups are excluded from full participation in society.

So in the modern nation state, the notion of citizenship is multi-layered and fragmented. Lister (1997) and Phillips (1991) argue that citizenship is only fully realised through political participation. But as the mechanisms of modern democracy in the UK are seen as increasingly dysfunctional (Cooper et al, 1995, Stewart, 1997) one interpretation would be that this is the result of outmoded processes continuing to operate. Experiments in new electoral processes, including proportional representation, extending postal voting and electronic voting only partially address the issue, failing to acknowledge the ineffectiveness of elections as a means of aggregating public opinion on individual issues. Voter turnout at general elections has declined from 82.5% in 1951 to 59.4% in 2001 (www.news.bbc/vote2001), while membership of the main political parties has shrunk from millions to around 300,000 in the same period. New modes of participation are supplementing and replacing the traditional electoral and party politics. (Giddens, 1997) The decline in political party membership has been accompanied by the emergence and dramatic growth in the membership of other issue based campaigning organisations like Greenpeace,

Amnesty and the Countryside Alliance as well as the dramatic growth in service user groups (Sang, 1998). In local and national government in the UK, they have grown in importance as the traditional model has declined, while the notion of democratic deficit (Cooper et al, 1995) in the health service has resulted in interest in that sphere. Papadakis and Taylor Gooby (1987) distinguish between voice, choice and control as alternative forms of participation. Many authors (Barnes & Walker, 1995; Charles & DeMaio, 1993; Croft & Beresford, 1990), differentiate between the role of the public as a user or consumer of public services and their role as a citizen.

Citizenship, according to Lister (1997) should be conceptualized as a practice in which what is important are processes of negotiation, contestation and dialogue through which claims and identities are constructed. Rights, obligations and political participation can only be meaningfully constituted through interaction and it is contestation and dialogue that constitutes the basis of democratic public spheres.

Taking a bottom-up approach Hall and Held (1989) have conceptualized citizenship as a fluid notion that is constituted through everyday talk and debate rather than being unproblematically defined. As a contested concept, citizenship manifests itself in and through discursive action.

It can be argued, as Mill (1947) does that participation is central to democracy. Habermas (1991) introduces the concept of the public sphere as the place where citizens meet to discuss and debate issues of collective concern is fundamental to democratic practice. The public sphere plays a legitimating and critical role in democracy by providing a venue for mediation between citizens and different interest positions. It includes the institutions of political activity, such as clubs and organisations in addition to the informal public spaces where debates and discourse may occur. The public sphere provides a setting for the development and exchange of

political opinion outside of the control of the state and other interests that shape society.

Within the public sphere, the citizen exercises rights to freedom of expression and opinions with equality of access. Clearly this is an idealised or stylized version of democratic practice, which neglects culture and identity and the limits imposed by education and access to resources, equally it ignores the subtlety with which political and economic power can influence opinion. Under contemporary capitalism, the public sphere had become debased by the transformation of the citizen into the consumer and the growth of media elites who, instead of facilitating rational debate, manage public opinion and limit discourse. More recent views of the public sphere have tried to incorporate these criticisms by re-conceptualising it as where discursive practices lead to refining of identity and clarification of interest. Within this new approach is an inherent pluralism of discursive arenas where identities can be negotiated and contested (Thomas, 2004). Mouffe consider that the presence of contestation (or what she terms agonism) is the productive part of the democratic participatory process (Mouffe, 1992). Kulynych (1997) brings together Habermas's vision of the discursive public sphere with ideas from Foucault about the nature of resistance to propose a model of participation that has as its method deliberation and contestation, and its purpose resistance.

The NHS Plan, New Labour's flagship health reform, puts this in the context of one of the modernisation theme of the Blair Government. The NHS is *"a 1940s system operating in a 21st century world"* (Department of Health, 2000: p. 5). Within the Plan this is interpreted as both an outmoded relationship between the professional and the patient/citizen and an outmoded relationship between the organisation itself and the citizen (Department of Health, 2000). This echoes Giddens (1997) view and in some senses, represents a return to classical democracy which was founded on the participation of citizens in government. Mill in

Representative Government writes that the best form of government is founded on

> *"every citizen not only having a voice in the exercise of that ultimate sovereignty, but being, at least occasionally, called on to take and actual part in the government by the personal discharge of some function, local or general"* (Mill, 1947;p 207)

Recent views of citizenship, have tended to stress the development of a more participative or active citizen. From the right of politics they have aligned citizenship with consumption, arguing that participation as a consumer of services is a means of exercising social rights. This, Prior says degrades the more holistic version of citizenship in that citizens are expected to self-interestedly compete for high quality services, rather than protect the rights of their peers (Prior et al, 1995; Salter, 1998). Other writers (Perri 6, 1997;Cooper et al, 1995; Stewart, 1998) concentrate more on developing new forms of participation, often less formal which make the relationships between governed and governors more continuous and inter-active. There is a risk that the effect of new forms of participation, such as citizen panel surveys and focus groups may be to further exclude some groups in society from full citizenship.

Wolin (1996) describes democracy as *"a project concerned with the political potentialities of ordinary citizens"* (p 31). Thus, like Mill he links the participation of the public to the realisation of democracy itself. The participation of citizens in the discourse or deliberation leads to the foundations of legitimacy (Benahbib, 1996b). This discourse theory of democracy emerges from a view of society in which the state is only one of many important institutions in the public sphere within which opinion formation and will-formation take place (Habermas, 1996; Benhabib, 1996a). As we have seen, commentators on the state of democracy in the UK have picked up the deliberative approach in discussing the need to revitalise democracy by increasing the participation of citizens in local and national decision-making (Stewart, 1998; Perri 6,1997)

But the model is not without its critics, a deliberative model conceives of citizens coming together to agree goals, ideals and actions within the public sphere in the context of equality and symmetry (Benhabib, 1996b). The participative element becomes central to the process of decision-making in society, democratic practice centres on collective problem solving through communicative action, rather than competitive individual resolution (strategic action). Implicit within the deliberative model is an assumption of collective understanding, a unity as Young (1996) puts it. If that does not exist, a deliberative model runs the risk or reproducing and reinforcing existing patterns of disadvantage.

As Young argues, the distinction between political and cultural forms of communication is not as sharp as Habermas suggests but that they are interconnected to identity and values (Benhabib, 1996b; Young, 1996). Mouffe argues for an alternative approach, in which the politics of difference are recognised. She stresses the contested nature of politics and the existence not only of plural positions within a polity, but of a plurality of identities and world views (Mouffe, 1996; 1999). The theory of communicative action and the notion of a deliberative model of democracy are seen by some commentators as being built within a white, male, middle class version of rationality, only one of the plurality (Campbell & McLean, 2002; Lennie, 1999; Mouffe, 1996).

Mouffe notes the impossibility of entirely freeing ourselves from differences in power. Recognising the importance of difference means recognising the existence of relations of power between actors in deliberation (Mouffe, 1996). Differences in power will mean that the values and world view of some individuals or groups tends to be preferred in deliberation to the exclusion of other views.

3.5 Power and policy making in the NHS

Power is a fundamental, but contested concept. It concerns the capacity to produce a desired outcome, but also is concerned with the process of producing outcomes. Aron(1986) distinguishes the French "pouvoir", the infinitive from "puissance", the participle; in English, the act from the potential. An understanding of the contestation of power is central to understanding policy making in the health service. If there were no persistent differences in power or the capacity to achieve desired outcomes, we would expect that over a period, health decisions would not favour the interests of any particular group or individual.

Arguments for involvement in decision-making rely on the view that in democracy, as Mill (1947) says, all citizens should participate in governance, that more participation is desirable. This is an endorsement of a pluralist perspective as the ideal democratic form. Richardson's view of the policy process in the health service is that it is a *"...process of discussion and negotiation between participants facilitates the decisions likely to prove more acceptable to all sides..."* (Richardson,& Bray, 1987: p. 14), in other words that it does rely on pluralistic bargaining. This is clearly at odds with Haywood & Hunter (1982) and many other analysts (Ham, 1999; Alford, 1970) who insist that there are systematic patterns of influence over health decision-making, with the interests of the medical profession occupying a dominant position by virtue of their monopoly of specific types of knowledge and their patronage by the state.

Empirical studies of power in communities in the 1950s and 60s (Hunter, 1953; Dahl 1961; Polsby 1980) attempted to identify the interests represented in decisions. Dahl concluded in "Who governs?" that in New Haven, there had been a gradual shift from oligarchy to pluralism over a long period and that at the time of his study, power was not concentrated but fragmented among many different actors. (Dahl, 1961) Dahl's study

was in part a reaction to others like Mills (1956) and Hunter (1953) who had concluded that both at local and national level in the USA, a comparatively small group governed the country.

Pluralists see the state as the referee in a process of bargaining between interest and pressure groups, including those representing consumers or users of public services. Policy is seen as emerging, very much in the form of the "shared vision" from the process. Later pluralists describe a multiplicity of competing groups and activity, but like elite theorists, recognise that some groups, the state, professionals and big business amongst them hold a privileged position and are able to effectively veto policy developments which they perceive as threatening their position. So, a few interests occupy very powerful positions in society, a "power elite" in Mills' term (1956) from which they are able to protect their interests, while remaining unconcerned with other areas of public policy making.

The pluralist approach, and to an extent elitism, is based on an empiricist model in which deliberations and decisions are observable. But what if all decisions are not made in the open and the most important decisions are taken in secret? Bachrach and Baratz (1970) develop the literature on power by introducing the idea that there are decisions that are taken behind the scenes to restrict the discussion of some issues. This they term the mobilisation of bias, a process which confines decision-making to issues that are unthreatening to those who control the process. Non-decision-making, that is a process used to manage conflicts and prevent issues that are threatening to the interests of the powerful from entering the political process. We get an indication of where this might occur from Skelcher's (1993) model of public involvement. Debates over issues peripheral to the interests of the powerful are in the "service" domain, where involvement is permitted and discussion is open, on the other hand, debates over "structural issues" have a major impact on the interests of professionals or service organisations and are possible sources of conflict

between the powerful and the public and are unlikely to reach the public stage.

Lukes (1974) views this too as an overly behavioural model and seeks to further extend the debate into what he terms a third dimension. His perspective is that the system is sustained not only by observable decisions but also by the socially constructed and culturally patterned behaviour of groups and the practices of institutions. In the third dimension, power is used to shape preferences so that neither overt, nor covert conflict exists. The wielder of power influences, shapes, and determines conceptions of the necessities, possibilities, and strategies of challenge in situations of latent conflict (Gaventa, 1980). Conflict would only become observable if those over whom power is exercised to become aware of their true interests. This is unlikely as institutions such as the agencies of socialisation are controlled by the interests who consciously or unconsciously reproduce the perceptions and cognitions that serve their interests.

Studies of organisational power have offered some support for Lukes' view. Pfeffer (1981) for example found that one of the critical tasks of managers was the construction and maintenance of meaning through a shared belief system. This could then be employed in the construction of the rational and as a way to legitimise decisions. Similarly, Ham's study of health policy in Britain shows that the dominant value system of the health field favours the medical profession and that even though other models of health exist, issues are defined in a way that favours doctors and the medical model and they fail to influence health policy significantly (Ham, 1999).

In Freire's, analysis of the dynamics of power, those who are silenced by power's third dimension are the oppressed. They *"speak with a voice that is not their own"* (Freire, 1970:p. 34). Their consciousness is conditioned

in the interests of the powerful. They are not only powerless, but reconciled to their powerlessness, perceiving it fatalistically, as a consequence of personal inadequacy or failure. However, the apparent domination of one interest may have other roots than the reproduction of preferences that serve that interest. Looking from the position of the oppressed, Saunders' (1980) study in South London found that the failure to mobilise working class groups was rather the result of fatalism about the likely success of political action rather than an inability to recognise their true interests. This is a perception not of personal failure, but of the inadequacy of the political system to pursue their interests. The fatalism is about the possibility of change.

Structural explanations of power do appear to be deterministic, concentrating on the puissance, rather than the pouvoir. But for Giddens, this begs the question of how and where the structures originate, how are they formed and how they evolve? He theorises that the process of structuration is how, through the actions of human agents, the rules, practices and routines of the social system are produced and reproduced. (Giddens, 1986; Watts, 2003) Power, for Giddens is the transformative capacity of actors and built within the systems is what he calls a "dialectic of control" (Giddens, 1986 p39) by which he means the capacity of the weak overturn the structures of the powerful. This is a possibility because all actors have some of the resources that can enable them to contribute to structuration, contrary to the apparent beliefs of the South Londoners. According to Giddens, power can shift as the rules, practices and routines are modified rather than through a direct confrontation. Bourdieu's explanation is that the actors' motivation comes not from an external objectified purpose, but from their interpretation of the actions open to them which are themselves the result of the past and present actions of others and the social relations that are constructed through them. The South Londoners in Saunders' study have learned that to attempt political action is futile as their access to *current* institutions is poor, but their

contributions (action or inaction) will ultimately affect future practices and institutions (Bourdieu, 1982; Degeling & Colebatch, 1997). The implication for this research is that involvement in decision-making may not only alter the decisions themselves, but will ultimately change the NHS and perhaps not only the health service but the state as a whole.

The dynamics of power as conceived by these authors stands in contrast to the structuralist explanations and appears to offer plausible explanations of the interaction between the actions of individuals, social practices and the shape of institutions. Power, as conceived by Giddens, can be a positive as well as a negative force, transforming structures, that is evident in all actions (Hardy & Leiba-O'Sullivan, 1998) and operates both top-down and bottom-up. The exercise of power may privilege some, but within the world of social networks, individuals and groups, including those who may appear to be repressed may exercise power through their application of knowledge or negotiation. Foucault considers everybody able to exercise power by drawing on the resources they can command (Foucault, 1994) and like Barbalet argues that power is co-constructed with resistance, arguing that without resistance, there is no exercise of power (Barbalet, 1985; Foucault, 1994). Those who are able to call upon fewest resources are nevertheless still able to exert influence. *"Every power relationship implies, at least in potentia, a strategy of struggle...."* (Foucault, 1994: p.346). Foucault's concept of resistance can be applied to participation. What Kulynych (1997) calls the micro-politics of resistance, which takes place in interchanges where power is exercised. In the pervasive nature of contemporary power, there already exists a possibility for resistance wherever power is exercised. There are no relations of power without resistances; which are more real and effective because they happen at the point where power is exercised. The act of resistance provides a meaningful sense of "citizenship" and Kulynych (1997) regards it as a successor concept to Arendt's notion of political

action, resistance or participation represents a primary vehicle for spontaneous and agonistic challenge to authority.

The contribution of these theorists is to extend the notion of power so that we recognise that power is part of inter-personal relationships as well as societal and structural ones. Accepting active and universal power raises the question of *how* it can be exercised, particularly for those who lack significant resources. Arendt's conception of the formation of collective will through discourse, rather than the imposition of one person or group's will offers a potential model for participation (Arendt, 1986). The communicative action perspective is taken on by Habermas who argues for the ultimate dominance of communicative action over strategic action, consensus over conflict as the foundation of the deliberative democracy (Hodge, 2002). However this raises questions of how it is possible for those who lack intellectual or physical resources to participate. For Pellizzoni, there are two aspects that are important, admission to communication and contribution to the dialogue or who may speak and how they may speak. This perspective is particularly useful, shedding some light on the process of involvement (Pellizzoni, 2001). The process of participation may be governed by a more or less explicit framework of rules and customs. The rules may be quite informal and are always subject to interpretation, however they describe, more or less the boundaries of the relationship (Clegg, 1989). In the context of public participation in political processes, the rules of elections are relatively clear and widely understood, but less formal forms of participation may be emerging new practices or institutions without clearly articulated rules or practices. Participants in programmes of public involvement in health service decisions may take part because of the nature of their condition, the location of their home or their allegiance to a group. Within the dialogue, their contributions may be controlled by rules of conduct within formal meetings, a set agenda or the context of the discussion and/or the positions of others in the discussion. In any case, their participation in

formal decisions is likely to be constrained by the practices and rules imposed by institutions, including those imposed through the third dimension of structural power. It is constrained also by the resources available to the participants. The ability of citizens or patients to realise opportunities for participation will partly depend on the skills and expertise of the public, their experience of participation and the support provided by institutions for developing participants' ability to take part.

Shifting the perspective to look from the point of view of the state, is helpful. For Foucault (1988), the idea of governmentality refers to a situation in which society is ordered in a de-centred way, and its citizens play an active role in their own self-governance. It means both strategies of governance, as well as self-governance by those who are the subjects. In such societies there is a concern with both individuals and groups. Governmentality is concerned with the mechanics of government, the technologies and rationalities, the totality of practices, through which the state rules. It represents a way of thinking that presumes that everything can and should be managed to ensure the efficient functioning of society. Schofield refers to a *"form of power that sets out to structure the actions of others"* (Schofield, 2002: p. 666), whereas Marinetto (2003) stresses that it represents the notion of democracy as practice rather than ideology.

This approach views government, not in the conventional sense as the function of centralised institutions, or the result of discourses where interest groups and ideologies play their part, but as a complex and unstable process that links ways of thinking about governing to the practices throughout society.

Modern approaches to government work through complex webs of technologies, including encouraging people to become self-managing (Gilbert, 2001) and for Rose (1996) have come to incorporate "community", which has developed as a new focus for social programmes

and a new and efficient means for structuring and regulating the population. So community participation and active citizenship act as strategies enabling the state to function more effectively.

Marinetto (2003), discussing local government and regeneration argues that community involvement in decision-making is one of the latest developments in the technologies of government, not working through its centralised institutions, but through dispersed regulation practices throughout society. Despite this, what we see today is not a reduction of central state control but a shift from the formal to more informal practices of government and the appearance of new actors such as the voluntary sector and active citizens.

So the question for this research is whether the broad emergence of public involvement in decision-making represents a genuine shift towards a more plural democracy in which members of the public and service users can have an impact on the pattern of public services or a new technology for management of conduct.

Power and the health service

Foucault also identifies a situation where the result of the struggle is that one adversary consistently achieves their interests. A state of domination represents a power relationship that is stable, accepted and settled. (Foucault, 1994) The existence of a state of domination in health would mean an acceptance of the hierarchy and leave no room for participation by the public in decisions. Many theorists have maintained that the medical profession has effective control of definitions of health and therefore maintains a privileged position vis-à-vis policy development (Eckstein, 1960; Friedson, 1970; Lupton 1994; Salter, 2003). It can be argued that some policy groups have achieved access to the margins of the policy community, but others remain excluded.

One explanation, consistent with a thesis of domination would be that it is those groups who work within a medical model of health that are able to access policy communities, whereas those who offer a challenge, preferring a social model of health based on lived experience are unlikely to do so. The medical profession has been able to appropriate decision-making in the medical encounter (Lupton, 1994) and imposed its preferred model of health and illness. As Harrison and colleagues put it, *"Much of the time doctors rely on the manipulation of the 'common sense' or 'traditional' ideas".* These are the *"concrete advantages armoured by ideological dominance."* that protect the medical profession's dominance of the policy area. (Harrison et al, 1992 p.85)

Haywood and Hunter identify an "iron triangle" of interests that dominate policy making. At the apex of the triangle is the medical profession, with the political and administrative arms of the state in support, legitimating the position by granting the profession autonomy in qualification and regulation. (Haywood and Hunter, 1982) For Friedson, medical power is a social construction based on the possession of expert knowledge and the central and dominant role in the provision of health services. It is manifest in the acceptance of bio-medical definitions of health and illness and is evident at three levels. At the micro level through the exercise of clinical freedom, at a mezzo level through the corporate relationship with the state and at a macro level through the ability to define health and illness and maintain status as the sole source of competence in health care. (Friedson, 1970). This kind of stable relationship among those involved in policy making, characterised by shared values and beliefs and resilience is often regarded as a "community" (Coleman & Perl, 1999; Radaelli, 1999). Within the health policy community, the role of the iron triangle and particularly the medical profession is crucial (Salter, 2003). Eckstein, in his study from 1960 found that it is the medical profession, particularly their collective voice that controls the development of policy in

the health service (Eckstein, 1960). Salter concludes that medical power is ingrained in the operation of the NHS (Salter, 2003). Even perceived challenges to medicine such as the development of the internal market in the early nineties which excluded the medical profession, eventually relied on them to sustain progress (Cairney, 2002).

Jones links medicine to colonisation by the welfare system of the Habermasian "lifeworld", Medical expertise has both positive and negative effects, both meeting the needs of those in ill health and playing a major role in the systematising tendencies of late modernity (Jones, 2001). The specialised language of medicine has the effect of excluding the public from involvement in health debates which are dominated by experts and those proficient in the technical language of medicine.

The issue of the distribution of power in society, and in particular in health policy debates is taken up by other authors who acknowledge the small and consistent group of powerful actors in decision-making. They are not only able to wield power and control policy-making, but are able to control who else can do so. In the corporatist version of elitist theory, the state offers status to selected interest groups, like doctors, in order to manage increasingly complex decisions in civil society. In return, the included groups offer assistance in managing society and maintaining the state system. This is the case in the creation of the medical profession as a state-licensed elite. The state protects the profession by legislating on medical practice and the profession maintains broad support of the system of government. The role of the medical profession in the debates at major paradigm shifts in health policy such as the Lloyd George National Insurance legislation, the NHS Act and the 1990 reforms (Day & Klein, 1992) is evidence of this relationship in action. In contrast, no organisation representing the interests of patients or consumers is granted similar access. Corporate bodies hold world views similar enough so that the regulation by the state is light touch, relying on the coincidence of aims

and values. Though sometimes offering slightly varying perspectives, the ideological partners will support each other and may be able to radically change policy. When corporate partners disagree strongly, as the government and the medical profession did initially over the NHS Act in 1946 and the Working for Patients white paper, the scene is set for a bitter battle. Day & Klein (1992) describe the struggles between the government and the medical profession at these crucial stages of health policy and conclude that while the 1946 Act may have ultimately been (in Websters words) a "triumph for the profession", the Thatcherite reforms were much more of a struggle in particular for the BMA (Cairney, 2002; Webster, 1990)..

In his classic study of the New York hospital system, Alford makes it clear that within the system there were three broad structural interests. These are characterised as the dominant interests, the medical profession who are served by the status quo; a challenging interest, that he calls "corporate rationalisers" made up of government, hospital management and owners who are concerned with changing the status quo to take account of technical and societal change, but not necessarily challenging the professional definition of health and illness; and the repressed interest of the community, whose interests are not served by the status quo. Allsop (1995) and Ham (1999) have argued that the model is relevant to policy making in the NHS, while North (1995; North & Peckham, 2001) examines this claim in more detail. North concludes that the Alford model provides a reasonably close fit to the NHS although the challenge of the corporate rationalisers is seen as gaining ground since Griffiths, while in later work, she and Stephen Peckham see the development of primary care groups and trusts in terms of incorporating professionals to the corporate agenda in the form of "professional rationalisers" (North & Peckham, 2001).

The challenge of the corporate rationalisers highlights the possibility of changing patterns of power in health services and in society. Despite their empowerment since Griffiths, there remains little evidence that managers are granted the same legitimacy as doctors on a cultural level. Social surveys put doctor's status much higher than managers or other groups of professionals (Harrison et al, 1992; BMJ, 2002) despite high profile scandals such as Bristol, Alder Hey and Shipman. North and Peckham's conclusions might indicate that they have succeeded in aligning their agenda and that of doctors. Some writers now suggest that the empowerment of the public, the repressed interest in Alford's terms is taking a similar path to that of the corporate rationalisers (Coulter, 1999). However it can equally be argued that the interests of the public are at odds with those of the medical profession and the managers, so that consensus is less likely. This is an issue taken on by the public health movement.

3.6 Health Development and Empowerment

The delivery of health care has been criticised by the public health movement for emphasising treatment over prevention. This has tended to result in the medicalisation of areas of ordinary life and reliance on experts that removes a sense of individual control over ones own health (Downie et al, 1990). A reaction to these trends has come from public health and health promotion professionals who subscribe to the World Health Organisation Health for All Principles which emphasise health as a social phenomenon (WHO, 1985). *"Those involved in health care and health promotion must...begin to work through the community rather than on it."* (Downie et al, 1990). It has also become the prevailing approach in the Health Action Zones set up by the government in 1998.

Participation is a fundamental part of the community health development approach and the new public health movement. In many communities

across the country, particularly among disadvantaged communities, (O'Keefe & Hogg, 1999) health initiatives drawing on the Health for All principles have been supported by public health and health promotion professionals (Ashton & Seymour, 1988) and there are now many hundreds of similar projects across the country and around the world (Lupton et al, 1998). Many are entirely or mostly independent of NHS services and some enduring over many years (Ewles et al, 2001) A key aspect of community health initiatives is their autonomy and their ability to identify their own health needs and develop strategies to meet them (Dun, 1991).

Community development treats participation as interactive and spiralling, increasing both in terms of numbers and depth as it progresses (O'Keefe & Hogg, 1999). Community participation, support and social networking are recognised as empowering and associated with improved health, while increased morbidity is associated with lack of social control, self-esteem and social support (Fisher et al, 1999; Wharf Higgins, 1999).

Bracht & Tsouros, identify other benefits from participation in community health development in terms of developing community resources, skills and support mechanisms (Bracht & Tsouros, 1999). Recent developments in this field have included the emergence of a literature on social capital, which Portes has defined as *"the ability to secure benefits through membership in networks and other social structures"* (Portes, 1998: p. 19). Broad assessments of what is included under the social capital label include political participation and membership of help giving and support organisations (Hawe & Shiell, 2000).

Within these communities, aspects of health decision-making are clearly heavily influenced by local people, however these decisions may be limited to those that have impact within the limits of the initiative itself and the bargaining among communities and between health development and

other funded services may be affected by inequalities in power and the dominance of the medical model of health.

Additionally, those actually participating in the activities may receive benefits that others in similar circumstances do not. Bracht and Tsouros (1990) conclude that many of those involved will be from community elites, in other words those community members already empowered. There is conflicting evidence in this area, Couto's review of the research found that some studies reported that participation promoted empowerment, whereas others suggested that a sense of empowerment promoted participation (Couto, 1998). Other writers have reported that the process of empowerment is dynamic and stems from the recognition of the forces of oppression that stimulates action (Bookman & Morgen, 1988).

Given this conclusion, it seems likely that empowerment emerges at least partly from the recognition that pluralist notions of power in society can be discounted. Within community health initiatives, community initiatives may be able to challenge entrenched power structures, but community members may not also be involved in, or able to influence more strategic policy decisions. It is also questionable whether community health development initiatives, which tend to be built on an alternative model of health, are likely to gain access to mainstream funding when decisions are made by NHS bodies that focus on biomedical approaches.

More complex views on structural power admit the possibility that actual decisions are only one part of the story, as the overt agenda for decision-making bodies may not encompass issues that challenge the status quo (Bachrach & Baratz, 1970) or medical definitions of health. Lukes suggests that there are cultural processes and social structures in which power acts in the three dimensional space defined by decision making, agenda shaping and preference shaping (Hay, 1997). This action works to not only prevent some issues being discussed, but also to prevent their

recognition as issues. The participation of community members in decisions may then serve to reproduce existing hierarchies and patterns of dominance (Hogg & Williamson, 2001). However from the perspective of those who concentrate on the exercise of power, the process of local involvement is a process of resistance, and will change the existing pattern of structural relations.

3.7 Three Approaches to Public Involvement

Literature that focuses on public involvement in health decisions tends to identify three broad stimuli for the development of public involvement, improvement in quality of services, improvement in accountability for decisions and improvement in health and well-being (Barnes 1999; Barnes & Walker 1995; Harrison & Mort 1998; Lupton, Buckland, & Moon 1995; Lupton, Peckham, & Taylor 1998; Rowe & Shepherd, 2002).

Strategies for improving the quality of services come from one of two traditions, those that adopt consumerist approaches, drawing on the experiences of private sector consumers (Calnan & Gabe 2001;Hood, Peters, & Wollmann 1996) and those that draw on the development of emancipatory social movements (Barnes 2002;Offe 1985).

There has been a dramatic growth of consumer organisations aimed at improving the interaction of the patient and the public with health services, and there has been a more radical growth of service user movements who have also sought to achieve change in the services they use, but have also aimed to establish their civil rights (Barnes & Shardlow, 1997). These bottom-up movements have been matched by the growth of a professionalised managerial stratum of the health service who argue that by involving the public and service users, you are able to identify and respond to their needs and wishes and to improve the quality and functioning of services (Seargeant & Steele, 1998).

The second premise relies on an analysis of the state of democracy and citizenship in the UK. It is argued that the relationship between policy makers and the public is, tenuous at best, and that there is a consequent "democratic deficit" in the health service (Cooper et al, 1995). Managers in the health service have recognised this deficit and have sought to secure local legitimacy by developing a range of new approaches to interaction with the local public (Sabin, 1992; Jervis & Richards, 1997).

Stephen Harrison has written that public involvement in NHS decision-making is part of the *"logic of democracy"* (Harrison, 1997). Bevan might well have agreed, but the agreement would hide a very different view of the meaning of democracy and the place of the citizen within it. The Bevanite view would be of democracy as bureaucratic and representative, in which the citizen was essentially passive, whereas by the late nineties the prevailing vision was of a citizen as an active participant in governance at local level.

Lastly, many public health analysts contend that participation itself has direct health benefits through improvements in self-esteem and social interaction (Wharf Higgins, 1999; Wallerstein, 1992). Public health professionals and health promoters have been strong advocates of this view of participation, arguing that as a result of social exclusion and inequalities, whole communities are denied access to health by social and political structures that act to marginalize them.

3.8 Implications for the research

There are a number of areas for research that are highlighted by this review of the literature. Firstly, the research must identify the origins and motivation for public involvement on the part of the NHS, what managers, clinicians and politicians hope that involvement will achieve. This will

mean examining perspectives on the precipitating, pre-disposing and enabling influences. Also, it will be important to examine what is the motivation of citizens and service users for becoming involved, what are their feelings about the process, what do they expect and to what extent are their expectations realised?

Second, the research should investigate the opposites of Abelson's (2002) influences, the barriers to involvement in decision-making, this will include the influence of existing patterns of power and domination in society in general and in the health service in particular. It should go on to examine whether and how barriers can be overcome to enable members of the public and service users to participate.

Thirdly, the research needs to examine the processes and outputs of involvement and whether decisions are taken differently or are themselves changed as a result of the involvement. It will be useful also to apply the conceptual framework to the examples of public and service user involvement fond, to classify them against the four dimensions of the framework.

Finally, it will be important to examine wider influences and impacts such as the influences on the development of specific examples of involvement and whether the experience of involvement has changed the way in which the health service operates and for those who participate, whether it has a personal impact on their lives and their health.

Chapter 4: Research Methodology

4.0 Introduction

In this Chapter, I will begin by describing my involvement in the development of public participation in health service decision-making and my approach to research. I will then discuss the research process, develop ideas on the importance of methodology in health service decision-making and describe and justify my approach to the research.

At the time I began this research, I had been involved in developing participation in health service decisions for almost ten years and in health and social policy development for somewhat longer. I joined the NHS in the late 1980s as a policy analyst and researcher, having worked previously in welfare research and policy development in the USA. While living in a small New England state, I had observed what appeared to be a much more intimate relationship between the citizen and government, annual town meetings which made crucial decisions were part of it, but in general people seemed much more connected to the democratic process than in the UK.

Much of my work in the public policy field had been survey research. It had included surveys of the views of clients claiming welfare benefits and users of family planning services on the services that they received. I was asked to help analyse notes from a series of meetings held to establish local views of health services in the Hartcliffe area of Bristol. (Ewles et al, 2001). I was struck most by the coherence of local people's views on their health which stressed the importance of environmental and social roots. Their views appeared to be at odds with, and incompatible with, those of health service managers who tended to be concerned with the maintenance and functioning of a health system rather than the effects of

services on the health of the community. This was at the time of the NHS reforms following "Working for Patients" (Department of Health, 1989) which introduced the "internal market" to the health service and separated the organisation of the provision of services from planning and local policy making, carrying the possibility for a different approach to health service policy making which was not driven by the need to maintain hospital services but could focus on the needs of communities. In my MSc thesis, which drew on the Hartcliffe work (Shepherd, 1990) I suggested that local involvement was possible and desirable for the "purchaser" of health services but that it was contingent on a paradigmatic shift in thinking about health being accepted at a local level. As a whole, my MSc studies exposed me, for the first time, to discussions of social change in the late eighties and I was influenced in particular by the work of Paul Hoggett and Robin Hambledon as well as others at the School for Advanced Urban Studies in Bristol. Their ideas strengthened the view that the local health service was becoming more and more out-of step with the changing relationship between the citizen and the state. Subsequently, added to my work plan was to develop processes for involvement in health service planning and decision-making in the Bristol area (Shepherd, 1995; 2001). I also participated at regional and national level in policy development, including a secondment to a small team leading the development of public involvement across the South West.

The policy rhetoric emphasised the role of the public throughout the 1990s (Department of Health, 1991;1998b;1999; NHS Executive 1994;1995;1996;1997; NHS Management Executive, 1992) but development was slow at local level and public involvement was one of several conflicting themes of central policy making, which for the most part had a low priority.

After 1997 and the change of government, the pace of policy change quickened still further, (Department of Health, 1997; 1998a; 1998b; 1999;

Department of Health & Neighbourhood Renewal Unit, 2002) and although the changing structures of the NHS led to a number of re-designs for the case study part of my research, the research questions remained the same, continuing to focus on whether policy development at a local level reflected, or at least included, the public's views or remained dominated by more traditional discourses.

This research was born out of my perception that despite the rhetoric and policy initiatives, little had really changed at a local level and that where it happened, public involvement predominantly served the existing dominant interests of the health service.

4.1 The Nature of Research

Research, according to Williams & May (1996) is a systematic process of focussed investigation, involving value judgements and the application of methodologies or techniques. The choice of techniques is dependent on the nature of the phenomenon to be investigated and the resources available to conduct the investigation. For the National Health Service, while these ideas underpin their view, research is described in terms of its characteristics, including the "newness" of the knowledge, the application of the knowledge to similar situations and the intention to disseminate (Bristol North PCT, 2003). The Department of Health offers a similar view, defining research as *"...the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods."* (Department of Health, 2001: p4).

These definitions are informed primarily by the traditions of clinical research in which the focus is on linear notions of cause and effect; whether or not a given dose of a particular drug or a given treatment results in measurable changes in bodily function. The aim is to observe the effects of "interventions" on the human body, and investigators are

able to devise experimental designs that allow them to identify and measure cause and effect. Techniques such as randomisation enable comparisons of results from exposed and non-exposed "subjects". Experiments are repeatable; results are defined, observable, capable of interpretation and generalisable to other subjects. Control over conditions is established by the researcher who is however exogenous to the processes under investigation, an observer, unable and unwilling to influence outcomes.

This approach to research has its roots in the positivist traditions that consider knowledge as established through observation of physical or indeed social phenomena, which will reveal universal laws. The positivism of the tradition of scientific and medical research has been criticised as founded on misconceptions of reality. Positivists hold that knowledge has its origins in experience, which can be objectively defined and understood. As Lupton points out, knowledge is not neutral but is rooted in scientists' own belief systems, developed in the context of their own professional interests (Lupton, 1997). Additionally, the interpretation of experience will differ from person to person, however minutely, depending for example on their physical abilities, cultural background and prior learning. These are components of a theoretical filter through which observation is made. Within social sciences, differences in interpretation of experience are likely to be greater than in the natural sciences given the inability to control the environment within which research takes place. Indeed, even within medical science, despite common values and understandings of the nature of the world (Lupton, 1997), major differences of interpretation often occur, for example over the cause of complex conditions such as autism or the adverse effects of vaccines, while major shifts in thinking occasionally come about through the accumulation of evidence, for example in the gradual acceptance of the bacterial roots of gastro-intestinal disease (see, for example www.faseb.org/opa/pylori/pylori.html, for a brief history of the debates). There are also differences between

even quite similar cultures in understandings of the body and the efficacy of different interventions. For example, Payer (1990) compares medical practice in Europe and the USA. She found that doctors in the USA tended to use more aggressive, often more invasive treatments, while European doctors tended to be more conservative.

Positivism privileges some kinds of knowledge, notably that produced through experiment, over other forms. The biomedical view is that experimental evidence is the most valued form of knowledge, so that knowledge construction is restricted to those who are conversant with experimental approaches to research. Professional understandings are the result of, among other things, personal background, training and experience. However professionals also share norms, values and ideas such as the autonomy of nature and its separation from society and the distinction between the individual and the culture (Lupton, 1997; Solesbury, 2002). These understandings have the effect of defining knowledge as professionally produced and devalue the contribution of other perspectives, including lay knowledge.

The devaluing of lay knowledge disempowers those working outside the biomedical or positivist paradigm and ensures that control over decision-making in the health service remains with professional experts (Lupton, 1997). However, positivist knowledge is also accepted among managers as the most valid form. Fraser and Lepofsky (2004) note a similar trend in regeneration, where even though local knowledge is acknowledged, it is expert knowledge that is viewed as more valued, despite the embeddedness of local knowledge within the environment and community, expert knowledge *'...appears to transcend these historical- geographic boundaries..."* (p7) to reveal universal solutions. In a similar vein, Kaati et al (2004) illustrate how professional judgements, based on positivist conceptions of knowledge dominate health decision-making in Sweden.

Within the professional context, evidence based medicine is a phenomenon that has evolved a hierarchy of research which places meta analysis of systematic reviews of randomised controlled trials as the highest form of evidence (Davies & Nutley, 1999). For medical professionals and perhaps also for health service managers (Labonte,1997), this provides an approach that accords with their scientific training, a rational model of decision-making and shared values. However while this may apply very well to the individual level evaluation of drug treatments, the importance of population level context in social policy research and the complex reality of decision-making makes it unsuitable and potentially misleading as an approach (Dobrow et al, 2004). Furthermore, the component research projects of a meta-analysis of clinical trials may be included on the bases of the subject and quality of research, without any significant attention devoted to the underlying theoretical basis for the original research (Stame, 2004). Muir Gray (2004) attempts to decouple evidence based medicine from evidence based policy making, which he claims is reliant on evidence from professional experts, but is dependent on values, the province of the public or elected representatives. What he fails to acknowledge however is that values in health care are not determined entirely without the influence of medical opinion, or that evidence presented by professionals is not value free.

In his review for the Health Development Agency, Marks (2002) stresses the epistemological and methodological roots of evidence based medicine and criticises them as seriously flawed in that they make questionable assumptions about individual behaviour or the political environment within which policy is made.

Social constructivists or relativists argue whatever any individual believes is true for them, so that there is no separate reality but that constructed in the minds of individuals and there can be no fixed definition of an event or object, rather meaning is seen in relation to its social context. Their view

is that the foundations of knowledge are value laden and that the distinction between the "objective" and "subjective" views is unclear. Different ways of interpreting the world cannot be labelled as erroneous, since different lived experiences lead to alternate understandings. Accounts are wholly referenced to particular situations, individuals or geographies and specific to them, rather than "generalisable". Social situations, such as meetings, may be subject to quite different interpretations by those attending as each person interprets the events and discussions in relation to their own experiences. That does not mean that there is not a single version of the events that all could agree on if they all watched a video recording of the meeting, but it does mean that the effect on each individual would not be the same (Marks. 2002). In social situations people employ a range of "rules" which may have the effect of avoiding or talking around issues so that the true meaning is obscured. Garfinkel (1967) adopts a focus on the language people use, maintaining that social life is not only described through language, but is constructed by it. In giving an account of events, people are not only being descriptive, but also are being creative.

For studies of public involvement, where people who meet to discuss health issues may come from widely different backgrounds, these are attractive ideas as they level the playing field of policy discussions. Lay perceptions and those of experts are equally valuable and constructions of knowledge do not privilege the expert. The difficulty for the relativist social researcher is that there are no unambiguous ways to make judgements about meanings and so no account is privileged over any other. This means that the researcher should not generalise from one event or set of events to another, but can only report the generalisations made by respondents. This appears to reduce, if not negate entirely, the usefulness of social research for the purpose of policy development, and under Department of Health definitions, it would not be defined as

research anyway. If in reporting on a situation, nothing can be said about other similar situations, why report at all?

Arguments against adopting either a purely positivist or relativist position for this research are strong as both are inadequate as a practical basis for policy research, both positions do provide helpful insights and have a value in application to specific kinds of research. For example, experimental designs provide information about the nature and effects of drugs on the chemistry of the human body, though they cannot generate knowledge of the effects of the same drugs on human beings as individuals in their daily lives. The importance of the relativist position in policy research is that discourses are not only individual, but take place also in an institutional and group context such as within the public policy and political arena. In these contexts, they are often conducted in a coded terms in which the words used may be intended to obscure real meanings, making observation an unreliable source of knowledge. Contemporary post-positivists have accepted criticism of the positivist position as simplistic and overly reliant on the observable. Their modified position retains the commitment to the objectivity of the observer and a belief in a single reality with understanding of the influence of the researcher on his/her observation and the limitations of observation as a mechanism for understanding (Williams & May, 1996) while recognising the importance of values, background knowledge and the influence of the researcher on the observed (Robson, 2002).

Robson (2002) highlights two broad strands of contemporary social research, post-positivism and constructivism that are the successors to positivism and relativism in social science. The two traditions, he says come together in critical realism which can provide a model of scientific explanation which avoids both positivism and relativism. (Robson, 2002)

The realist position is that the development of a theoretical body of knowledge goes hand-in-hand with observational studies that attempt to critically describe non-random patterns. The relationship between theory and observation is dynamic. Theory provides a framework for research, which can lead to modification or refinement of theory. Theory can be seen as an abridged, generalised organisation of experience that serves as an initial frame of reference for action and perception. In a sense, all policy is theory as it makes prediction about change that will happen as a result of legislative or administrative action, based on generalised assumptions about the world (Pawson, 2001).

Knowledge is viewed as a social and historical product of development and change and may exist only within the context of a particular temporal, geographical or cultural situation. However the realist view is that the world has an existence beyond the limits of our observation. The task of the social scientist is to understand the way in which mechanisms work in conjunction with contextual factors to generate social outcomes (Sanderson, 2002). Reality can be seen as a complex multi-layered system composed of events that are experienced by individuals, other events that are observed and others that are not experienced personally or perhaps known of. The social scientific task is to uncover layers of social reality, which may arise from personal realities that are in turn informed by them, but theories and explanations of the social reality can only ever be imperfect and subject to adjustment or revision.

Pawson and Tilley (1997) identify a standard set of concepts that can describe the operation of any social system. These they term embeddedness, mechanisms, contexts, regularities and change. Their view is that

> *"the basic task of social inquiry is to explain interesting, puzzling, socially significant regularities. Explanation takes the form of positing some underlying mechanism which generates the regularity and thus consists of propositions*

> *about how the interplay between structure and agency has constituted the regularity. Within realist investigation, there is also investigation of how the workings of such mechanisms are contingent and conditional, and thus only fired in particular local, historical and social contexts."* (Pawson & Tilley, 1997: p71)

By embeddedness, they refer to the relationship between human actions and the assumptions that are built into them. Mechanisms link inputs to outputs, however one cannot understand how a computer functions by tapping keys, and seeing a sentence appear on the screen. The concept of the underlying mechanism is fundamental. What is going on inside the computer is complex, if fixed and predictable, but social mechanisms are less easy to describe or analyse although components of the mechanism may be identifiable. The notion of causation is particularly important. Within the physical sciences, cause and effect may, other things being equal, be straightforward and linear, where in social contexts, the embeddedness of human action means that understanding the relationship between inputs and outcomes will rely on additional knowledge and understandings of social reality. The idea of a generative approach to causality which acknowledges that mechanisms may work at a different level of social reality may be more appropriate (Pawson & Tilley, 1997).

Equally important in this approach to social research of the concept of context, signifying the existing rules, norms, relationships and institutions surrounding within which the social program is set. The last of the five concepts, change is particularly relevant in the context of social policy. The aim of social policies is to change the outcomes of people's lives. The task for the social researcher is to discover what mechanisms for change exist, how they are triggered and what conditions are necessary for them to operate.

Purely positivist approaches are inappropriate for policy research as like other forms of social research it takes place in uncontrolled settings,

where there are few opportunities for either randomisation or control, nor are questions always amenable to simply codified responses. For the realist researcher, the central question is what is it that we cannot see that results in what we can see? Underpinning positivist approaches is an assumption of pluralism: that decision-making takes place in an unrestricted context, where everyone's views are equal or referenced to universally accepted facts. Though this may not be accepted by social researchers, observations that provide evidence at one level *can* help clarify or expose deeper mechanisms of power structures and illuminate the context. So, in policy research, the approaches used must draw on social research methodologies, in particular the use of survey data to define the breadth of the issues and interview data to explore its depths and meanings. Quantitative studies and in particular surveys can be used to provide summary level analysis which can identify areas for more in-depth research of either a qualitative or quantitative nature in addition, they provide point-in-time snapshots of social phenomena that can be used as a way to assess change over time.

Qualitative approaches such as interviews, observation and documentary analysis involve a complex interaction between the researcher and the investigation, interaction with the subjects of research and interpretation of their experiences. While approaches may differ, the attitude of the researcher as a systematic investigator remains the same. What also varies however is the researcher's beliefs about the construction of knowledge and values. The objective of the research in this context is not the development of new knowledge, but the generation of new perspectives or hypotheses (Robson, 2002).

The researcher in policy research is not an uninvolved observer, the understandings generated by the investigation, the questions asked and how they are asked will depend on his/her frames of reference. At a different level, the relationship between the researcher and informant is

constructed within the context of existing power relationships in society Perceptions of the social position of the researcher and the informant may influence the content of the information exchanged and cannot be separated from them as extreme positivists might suggest. Responses from participants in the research too will be delivered through the screen of the individual's personal life experience, while the relationship between the researcher and the informant may be marked by perceptions of differences in power and status. In this research, my status as a health service manager was known to all interviewees, which may have influenced them and what they were and were not willing to disclose or discuss. I was also known by many of those I interviewed as a strong advocate of public involvement in health service decisions. This might influence their contributions, while the strength of my own beliefs may have influenced how I asked about particular issues or my reactions to, or analysis of, their contributions. While members of the public did not know me in the same way, they were aware of my status as a researcher and as a health service manager, which may have affected their contributions in a number of ways, whether it was to say what they thought I wanted to hear or to emphasise and promote their personal agenda in the hope that I could influence health service decisions. My own approach to interviewing may also have altered from informant to informant, depending on my own perceptions of their power and status.

The point of view and philosophy of the researcher will influence not only the phenomenon investigated, but also the detail of the investigation. Williams and May (1996) cite Margaret Thatcher's assertion that there is "no such thing as society, just individual men and women and their families" as an example of the importance of the frame of reference. She may not have intended this statement to be overtly philosophical, but the implications of this individualist view of the world for policy and for men, women, their families and society the 1980s and 1990s were enormous.

Nevertheless, in the study of the social world, the basic approach is the same as that of the physical world and concepts such as prediction, explanation and causality are equally valid if differently constructed. In social sciences, the control that the laboratory scientist can exert over the physical world is not possible so simple observations are unlikely to explain causal factors which may be crucially dependent on unobserved phenomena. A realist approach to science holds that explanations of the social or physical world are critical and transitive or developmental, while the world itself is "intransitive". In social science, especially in political or policy science this is problematic as structures do not exist independently of the people who produce or are produced by them and social and political change can alter the context significantly.

Social sciences are often seen as value laden with subjective and normative origins. Early social scientists thought that only value free social science could be seen as truly scientific. Mill predicted that with maturity in the social sciences would come objectivity (Williams & May, 1996). However later social scientists began to see values as the subject matter of social science and essential to good science. Also, the idea that "facts" could be discovered in the way that scientists had assumed, began to be questioned. In the physical sciences the certainties of Newtonian physics were superseded by Einstein.

Weber's position was that although a value free social science was not possible, the researcher must understand the inherent values and separately observe the activities of the society. So Weber (1974) concludes that the social scientist is value neutral, despite recognising the importance of values.

The researcher's own values will shape the framework employed, perhaps the methodology and the research questions. These values are treated in the same way as facts. Marxist analysis extends from a particular value

base that holds that facts are shaped by those who are most powerful in society and that this blinds the proletariat to their own material disadvantage. In Marxist research, the objectivity begins with the establishment of a framework of values or specific ideological goals.

Feminism challenges social science on the grounds that as historically, research was conducted only by men, it portrays only a male perspective and has excluded the female perspective (Morse, 1994). Feminists contend that women occupy the position of an oppressed group within society and that part of that oppression is the devaluing of female perspectives. Knowledge is recognised as a social product constructed within a patriarchal society. Material life and social structures set limits to understanding, so that what we do shapes what we can know. Male experiences, seen from the position of dominance are distorted, so it follows are scientific claims. Women, on the other hand, from their position of being subject to domination can see a less distorted reality. Unlike other epistemological positions, feminists regard rationality and objectivity as constructs of masculinity. For Griffiths (1995), the production of feminist knowledge is grounded in feeling, so that rather than seeking to overcome feelings in pursuit of objective knowledge, they become a source of understanding. For this research, the construction of knowledge, in particular the validity attached to various knowledges, has a particular importance. Lay perspectives on health and illness may be emotionally led, driven by personal experience, feelings and observation, which may distort risks and priorities. These views may differ sharply from those of "experts", including both health professionals and managers for whom the experience of illness is impersonal and external. Like the patriarchy, definitions of health are produced and maintained by the dominant medical view, which may claim objectivity, but it can be argued is equally distorted and distant. The managerial role is one of maintaining the smooth running of the system and responding to mandates of central policy. Questioning the dominant model, which may well be necessary to

achieve public involvement, may cause the maintenance role to become unmanageable, so that the cost of public involvement to the health system is inflated.

In one of the case studies compiled as part of the research, some interviews were conducted by colleagues from the Division of Primary Care, University of Bristol. We worked very closely together, meeting to agree topic guides and areas for exploration before the interviews, working together in focus groups, and meeting to discuss the analytical themes after the data collection. However, both of these people are clinical professionals, one a GP, the other a nurse. Their status, which was known to some of those they saw, may have influenced informants so that the interviews yielded somewhat different information than would have been the case had I interviewed these informants.

Social science is concerned primarily with the values of people and society - and it is this that gives social research its relevance. Values can enter the process at the level of the methodological position of the researcher, the choice of research problem, the selection of methods, the interpretation of evidence or the determination of conclusions and their dissemination. Research may be conducted with influence from the value framework suggested by, for example Marxism or feminism, but is most commonly in the context of a research question, which dictates appropriate methodologies.

A key goal for research is to achieve validity, which can be interpreted differently in different approaches. Survey research is said to generate greater "external" validity, that is a validity beyond the bounds of the research itself. It is generalisable to other settings. However, there are limitations to the level of understanding that can be gained through the collection of survey data. For example, the understanding of concepts involved or included in a questionnaire may vary from one respondent to

another, so that expressing "satisfaction" with services, for example in general practice may depend on expectations and other ideas such as gratitude and perceived social position that cannot be gathered by questionnaire but require more in-depth exploration.

Validity in qualitative research is constructed along different lines than those of quantitative approaches. Internal validity can be developed through the study design, for example by the use of independent sources of evidence to "triangulate" or seek convergence between sources. In these case studies, analysis will be based on original documents, press coverage, field notes taken at meetings and interview transcripts. Each piece of evidence will be subject to content analysis in the light of a thematic framework. This will involve coding or indexing of concepts or themes occurring within the text. Initially, this will be based on topic guides developed for the interviews, but as the analysis proceeds, additional themes may be added or the guide altered to help in triangulation.

It is in the area of external validity that qualitative research differs sharply from quantitative designs in that conclusions are not likely to be generalisable regardless of the context within which they are conducted. Instead, here as in much qualitative research, the purpose is to provide explanations and meanings of the context.

Participants in focus groups or interviews, for example, are able to develop arguments and interpretations that generate an understanding of expectations and other factors and how a visit to the general practice fits within the context of everyday life. The difficulty is in generalising these insights as they are specific to the particular conditions of the research setting. However, at a deeper level, they also provide information about structures that link to and underpin the expectations of services provided by general practices in the UK.

These two versions of validity can be used together within the context of a research project, with separate functions that both contribute to understanding of satisfaction in general practice.

The application of these perspectives to this research begins from the critical realist position that by application of survey methods, I will be able to uncover practice in public involvement in health service decisions at a point in time and assess whether national policy developments in this area have been associated with changes in the approach of local health authorities to decision making. The results of the survey work have limited use in developing understandings of the process or outcomes of public involvement in decision-making in the health service but will provide a baseline assessment for more in-depth study of the practice of public and patient involvement in health decisions using a case study approach. The case studies draw on interview, document analysis and observation to develop understandings of the place of the public in health service decisions in specific circumstances. They will enable me to contextualise involvement in decision-making and make comparisons between contexts as well as between the perspectives of health service professionals and participant members of the public. It includes the perspectives of those involved in public involvement in health service decision-making, both from the health service and from the public.

4.2 The Research Questions

The research questions for this work are bound up with the initial theoretical perspective. The context within which the development of public involvement has taken place in the last fifteen years is one in which the existing dominance of the medical profession has been challenged by the emergent managerial interest broadly supported by government policy. As I have argued in the preceding chapters, managerial ascendancy does

not challenge biomedical views of health or definitions of knowledge, however the growth of a community or service user interest which intuitively adheres to a social model of health challenges both the managerial and the medical interests.

The origin of the growth of public involvement in policy document is contested and I will seek to clarify or classify this growth from the contributions of those who have participated either from the public/user or managerial perspective. The research will explore and seek to develop this theoretical perspective by focusing on a series of research questions. The first area for the research was concerned with the origins and motivations for public involvement in health service decisions.

- Have health services developed public involvement to fulfil the requirements of government policy, health service managers or the public?
- What have been the principal drivers of developments?
- What effect has the growth of service user organisations had?
- What is the balance between local and central initiatives?

Next, I wanted to clarify the meaning of public and service user involvement from differing perspectives. I was concerned that what members of the public thought they were becoming involved in was not what health service managers thought they were offering involvement in. This will be addressed through the following questions:

- What approaches have been used and to what extent to they amount to involvement in decision-making?
- How do health services and the public interpret "public involvement"?
- Do participants see themselves as "involved in decision making"?

- Where and how do public views fit into the decision-making process?

Thirdly, the issue of the level of involvement are an important area of investigation. In traditional Arnstein's ladder terms (Arnstein, 1969) I was interested in whether programmes and projects for involvement reached levels beyond "manipulation", but I was also concerned with whether there were areas where involvement was not likely. Skelcher's (1993) approach suggests that this would be in "strategic" areas, but the limits might also be defined in other terms, perhaps around issues of access to medications or choices of service.

- In what decisions is involvement "permitted" by health services?
- Are there areas where public involvement is more (or less) appropriate?
- Is it possible to initiate involvement *except from* the position as health service management?
- To what extent is involvement concerned only with "window dressing", has there been the radical shift called for by policy guidance?
- Do managers use public views as serving their purposes or fulfilling broader aims such as empowerment or democratic participation?
- What are the limits to involvement for the individual manager and for the service user?

Finally, I wanted to investigate the outcomes of public involvement in terms of the decisions taken by authoritative bodies. At first glance, this might be a case of examining the correspondence between the expressed views of participants and the decisions taken, however if professionals and managers control the issues debated and the mode of discourse, it would still be possible that public views were repressed. Deeper insights into the

impact of involvement might be gained by discussions of the process of involvement with those involved, including mechanisms for participation, issues under debate and feelings of inclusion.

- Is there any evidence that public involvement has an impact on the decisions taken?
- Are participants able to influence the issues that arise in health service discourses?
- In which services or situations are the views of the service user or public most influential?
- Are members of the public and service users able to access the necessary information and skills to enable them to participate fully?
- Are there examples of changes directly attributable to public involvement?
- To what extent has national policy altered the practice at local level?

4.3 The Choice of Research Methods

When this research began, it was important to understand whether and how the NHS at a local level had taken on the challenge of seeking public views and including them in decision making processes. As Klein has written, for most of the first fifty years of the NHS, the patients were the ghosts in the machine (1987), but following the Griffiths (1983) report in the mid-eighties and the "Working for Patients" (1989) reforms of the late eighties and early nineties, the focus for service providers was supposed to shift to the "customer" or patient, while health authorities were charged with becoming "Champions of the People" (NHS Management Executive, 1992). Later, the NHS Plan (2000) promoted the idea of a patient-centred health service and new structures for involving people in decision-making.

In choosing to adopt a critical realist approach to the research, I both acknowledge the importance of observation and reporting, but also recognise the importance of the social and political context of the development of public involvement policy. A more positivist focus would seek to observe changes in decisions following public debate, hypothesising that debate can be linked to them, rather than that they are part of a complex set of circumstances and understandings within a social and political context. It might view participation in involvement programmes as a measure of "interest" or "concern" for health issues, rather than as deriving from expectations of the relationship between the state and citizens.

One aim of the research was to investigate changes in the decision-making processes as a result of the development of the involvement policies. Examining this required developing an understanding of the context of the health service, in which the role of the medical profession, local managers and government were important, as was the perception of citizens and service users of their role in and ability to impact on decision-making.

In 1998, when the research began, little literature was available to draw on to examine whether and how these challenges had been taken up. Only one published survey, by Obermann and Tolley (1997) could provide a broad picture of practice across the country, despite efforts by the Department of Health and others to gather information (NHS Executive, 1994). A few pieces of research, for example (Bowie et al, 1995; Shepherd, 1995; Milewa & Valentine 1996) gave insights into practice in specific area or detailed alternative approaches. This made it important to undertake a survey of all health authorities in England and Wales to find out whether progress had been made at a local level in developing public involvement in response to national policy.

Each phase of the research was designed with a specific purpose in mind. The survey aimed to provide the broad picture of the development of public involvement in the 1990s across England and Wales. The questionnaire proved adequate as a source of information at a summary level, identifying structures and policies in place, but it could not provide insights into the process of involvement or how the views of patients, service users and the public were included in decision making processes. This more focused and detailed work required a more in-depth approach. The aim would be to gather information from those concerned with examples of public or patient involvement work to assess what its effects were on decision-making and on those who participated. Although this could perhaps have been achieved at a general level, involving participants from a range of involvement efforts, these three pieces of work would, I believed provide insights into the specific settings, but would also generate a deeper understanding of public and patient involvement in the NHS.

Much of the research into public involvement was evaluative, with a focus on one or a few similar projects. Consequently, many of these questions have not previously been addressed sufficiently by researchers, nor was there available evidence about the approaches to public involvement evident across the country. In order to understand the place of public involvement in the contemporary health service, it would be necessary to gather comprehensive information about the extent of activity and examine a few examples in depth. This suggested two levels of inquiry, one, a survey designed to look at patterns in the health service across the country and the other, case studies informed by the survey to examine in detail a few key areas.

Survey Research Methodology

The purpose of the survey was to establish a baseline against which to understand the process of public involvement in the NHS and to identify areas for more detailed research. Detailed information about the survey methods and analysis of the results is included in the next chapter.

The questionnaire included both pre-coded multiple choice questions and open- ended opportunities to expand on answers. Responses to questions requiring detailed answers were grouped into identifiable themes and coded to facilitate analysis. These included the questions about processes undertaken to develop policy and to make specific decisions.

The questionnaire was sent to the Chief Executives of all Health Authorities in England and Wales in June 1998. It was divided into four sections, covering: the organisational context, including questions about the leadership of public involvement work, policies in place and people involved; public involvement activities undertaken and the training available in preparation for the work; the impact of involvement in a range of service areas and a number of other issues, including partnership work, funding and evaluation.

By October 1998, with two follow-up mailings to non-responders, a response rate of 92% (96/105) had been achieved. Two further health authorities sent letters declining to take part due to pressure of work. The response was consistent across the country, with the lowest response being in Anglia and Oxford Region (7/9, 78%). In Wales, North Thames and Trent Regions, all questionnaires were returned.

Responses were entered into PinPoint for Windows software (Cole, 1997) both pre-coded multiple choice questions and open- ended opportunities

to expand on answers. Responses to questions requiring detailed answers were grouped into identifiable themes and coded to facilitate analysis. These included the questions about processes undertaken to develop policy and to make specific decisions.

Selection of case studies

The theoretical and policy issues discussed in Chapters 2 and 3 and particularly the conceptual framework that theorises the dimensions of public involvement provide the beginnings of a basis for the choice of case studies. The crucial distinction between people as citizens and people as users of services suggests that both should be represented in the case studies. A second dimension that provides a possible distinction is that between direct and indirect involvement. Again, both sides of this duality should be represented in the case studies. These perspectives provided necessary characteristics, but were not sufficient to identify suitable areas for further study.

In the case study phase of the research, I wanted to investigate public involvement in a number of differing contexts, to describe a range of situations in which involvement takes place. The alternative approach would have been to compare involvement in similar contexts. As I wanted to compare service user involvement and public involvement in case studies, similar contexts would not have achieved this aim, nor would similar case studies have enabled me to look at both very local and more strategic decisions. I suspected that at a local level, different issues would come to the fore and that there might be more opportunities for involvement. Again, this promoted the choice of differing contexts for the case studies.

A number of the results of the survey of health authorities conducted for this research contributed to the identification and selection of case studies

for further research, although the final choices were made on an opportunistic basis, identifying specific instances and programmes of public involvement from my background knowledge of the field.

Skelcher (1993) suggests that decisions that involve challenges to strategic decisions may be the least likely to involve the public. These decisions are most likely to be taken formally by public bodies such as the Boards of health organisations. While people may be able to participate in the decision-making process, they are unlikely to be involved in the meetings where decisions are taken and their views are most likely to be mediated by health service managers or professionals. Unlike both of the other case studies involvement is indirect. So the case study will examine decisions taken across services about the overall direction of health services in a local area. I was asked to do some work for the North Bristol NHS Trust to involve local citizens in decisions about the restructuring of their hospital services. The work involved conducting focus groups with people who had shown an interest in the decisions. This gave me the opportunity to extend this work, with the Trust's approval, to a case study of involvement in the decision.

The majority of health authorities identified community development as one of the approaches they used to involve people in decision-making. This is an appropriate area for a case study because it involves people as citizens directly in decisions and also because it is often linked to health promotion and strategies for empowerment. Public health practitioners believe that involvement can have a direct impact on health (Bosma et al, 1997; Wallerstein, 1992). Other authors (Lupton et al, 1998) have also identified community health development as the area where there is the most potential for effective involvement so the second area for further study was chosen as community involvement in health improvement initiatives in areas of high health need. In Bristol, an innovative project for the redevelopment of primary care services in Knowle West, was

something I had been somewhat involved in for some time. The opportunity to be involved in further evaluative work arose through contacts with colleagues at the Division of Primary Care, University of Bristol and we agreed to cooperate. The "Health Park" had developed with a strong philosophy supporting involvement as a path to health improvement, fulfilling the needs of this case study.

The survey confirmed that there was more activity in mental health services than in any other area. Not only was there more activity in mental health services, but survey respondents felt that it had more impact on policy. Although the survey did not seek to identify the reason for this higher level of activity or for the additional impact, a number of characteristics of mental health services may go some way towards explaining why this might be the case.

First, mental health services are part of the joint planning apparatus, with local authorities taking a substantial part in the development of policy. The need for local authority policy to receive the approval of elected councillors means that there is a disposition towards participation in planning. Additionally, the presence of voluntary sector organisations in joint planning forums has meant the involvement of user organisations, including mental health organisations in the policy community.

Second, the existence of a strong and long standing mental health service user movement means that it is much more easy for health service organisations to identify and access service users and that the service users themselves are prepared to participate, being already familiar with structural features of the health services and the processes involved. So the first area suggested by the theoretical perspective and the survey was the involvement of mental health service users in decision making. I was introduced to user involvement in mental health services in Somerset by a colleague at the NHS Regional Office in the

South West. With an active service user movement, happy to be involved and a new and innovative structure for service delivery, this was an appropriate location for the study. The table below summarises the case studies.

Table 4.1 Case Studies in Public Involvement

Case Studies in public involvement	
North Bristol Trust	This case study examines public involvement initiated as a result of the decision by NBT to redevelop their acute hospital services. Involvement followed an initial planning phase in which the Trust's Programme Board had agreed a model of care that focused on very specialist acute services, backed up by services in the community. Involvement included public meetings, surveys and focus groups and occurred over the course of a nine-month period. Key issues in the case study include the level of commitment to real involvement within the Trust, the stage at which involvement took place, the view that participants took of the process and those running it on behalf of the Trust and the impact of local views on decision-making.
Knowle West Health Park	Knowle West Health Park is an innovative development in a deprived part of Bristol. It includes a new health centre, a healthy living centre and other services on a single site. From the beginning, the Health Park Project was conceived as involving local people in planning new services. Local involvement was evident from the start of the project, which was led by an idealistic group of professionals. The project took several years to come to fruition, but a number of local people have continued to be involved. Key issues in the Health Park include the importance of individuals, both professionals and local people, participant views of the process of involvement and the impact of involvement at different stages of the project
Mental Health Services in Somerset	Unlike the other two case studies, the third study looks less at the history of a specific project as at a particular service and the role of service users in a geographic area.

Somerset is an interesting area to research as mental health services there are provided by an NHS Trust that has integrated with the County Social Services Department. The Somerset Health Authority also established a reputation as a leader in the development of public involvement, through its "health panels".

There is a significant mental health service user movement in Somerset, although it is perhaps not as developed as in other areas. In the study, I look at the role played by service users at a local and County-wide level, in both informal and formal decision-making processes. I also identify specific policies and decisions that suggest the Trust's actual commitment to user involvement. From the service user's perspective, I also examine the possible impacts at a personal level.

Case Study Methodology

Yin (1994) identifies case studies as exploratory, in which the goal is to develop hypotheses for further enquiry, descriptive or explanatory. He states that the case study is a research strategy used to investigate a contemporary phenomenon, especially when the boundaries between the phenomenon and the context are not clearly evident. The design of case studies can include a number of different approaches to data collection and analysis (Yin, 1994). Case studies can focus on single sites for study or multiple site comparative approaches. (Burgess et al., 1994)

In the case of this research, the purpose of the case studies is to examine in detail how in differing contexts, local health services are interpreting public involvement and whether it has led to local people or service users having a significant impact on the delivery of services. The purpose of undertaking more than a single case study within a single programme of research is to enable comparisons between the different settings and to explore different aspects of complex issues. Yin considers that each study should try to "replicate" the case studies to enable comparisons

between them. The advantage of this approach is that it can assist in development of a rich theoretical framework. He contrasts this with sampling logic as an approach to multiple case studies. In this approach, each study would "represent" the universe of potential settings.

Others have also stressed the importance of cross-site comparisons and the extent to which data collection in one site could be informed by the thematic analysis of another. Burgess and colleagues provide a valuable discussion of the issues in research combining multiple case studies in different settings (Burgess et al, 1994). Concluding, that each case study can be seen as contributing to the overall research as well as being a research project itself *"...four studies in one, and one study from four."* (p143)

Each case study is constructed from a number of different sources of evidence. The use of a number of different sources can enable a process of triangulation or convergence, where different sources are used to provide corroboration of a particular view. Yin (1994) refers to this approach as one of the three principles of case study research. The second principle is to collect the evidence into a case study database, including all notes, transcripts and documents relevant to the case study. Yin's third principle is to "maintain a chain of evidence", meaning that conclusions and evidence should be connected through an audit trail which would allow an independent observer to trace the origins of conclusions. The use of a range of sources means that data collection is more complex in case study research than in other strategies, requiring versatility on the part of the researcher in both the collection process and in interpretation. Yin (1994) identifies possible six sources of evidence for case study research these are documentation, archival records, interviews, direct observations, participant observation and physical artefacts.

Not all of these sources are relevant to all case study research. The nature of public involvement in the NHS is such that there are unlikely to be physical artefacts relevant to the understanding of the topic, while most archival material will be in the nature of documents. The principal sources of evidence in these case studies will be documentary accounts, interview and focus group transcripts and notes from observations.

Documentary evidence is useful, not because it provides a complete or unbiased commentary on the topic, but to corroborate and augment other sources. The content and style of documents and their distribution provide evidence of organisational attitudes towards public involvement, while press releases and subsequent coverage may provide evidence of the organisation's perception of the public. The documents used in this research include the minutes of meetings, policy documents and other health service publications, reports written as a result of meeting held to involve service users or the public, written contributions to consultation papers and press releases and press reports.

All interviews and focus groups were recorded, using minidisk or audio tape. Recordings were fully transcribed both as an initial phase of thematic analysis and to facilitate full analysis. Transcripts of interviews held with health service managers, clinicians and other relevant agents of the statutory authority, and transcripts of interviews or focus groups with participants in involvement events and meetings provide a significant part of the evidence base. Observation of meetings involving service users and the public and at Board and other meetings of the NHS organisations involved also provide information relevant to the study. Observation at meetings involving service users or the public are an important source of evidence, providing information about the relationship between the NHS organisation and the participants. Observation at NHS meetings provide additional evidence of the attitudes of NHS staff to the public and public involvement away from public gaze.

Validity in case studies.

Four tests of validity are defined by Yin (1994) as:

- Construct validity, establishing the appropriate measures for the concepts under consideration. Construct validity relates mostly to the data collection phase of the study, and can be associated with the multiple sources of evidence used and the chain of evidence established.
- Internal validity, in which the relationships between factors of actors are established through explanation building and pattern matching in the analytical phase of the study.
- External validity in which the conclusions from the study are generalised to larger populations. External validity is enhanced by the use of statistical approaches to sampling and analysis, however in social research it may be more important that generalisations focus on deeper structures.
- Reliability in which it is demonstrated that the results are repeatable. Reliability is guaranteed by recordkeeping in the operation of case studies, by rigour in design and meticulous application of the design in the data collection and analytical phases.

The aim of the case studies was to examine in detail the process of involvement in a number of particular situations. Case studies are a method of social research in which multiple sources of evidence are brought together to explain or illustrate the phenomenon under investigation. The use of multiple sources is important in that it provides a means for triangulation of issues and values, shedding light on the same phenomenon from different perspectives is used both to confirm (or deny)

hypotheses and to further explain them. Denzin (1988; Macdonald & Tipton, 1993) identifies four forms of triangulation provided by multiple data sources; data triangulation, in which multiple data sources provide a means for mutual verification; methodological triangulation in which either within a single method, different approaches are used or where multiple methods are used to collect data; investigator triangulation, where more than one researcher collects data in the same situation; and theory triangulation where different perspectives are brought to bear. In the main, my research relies on data triangulation, although I was fortunate to work with other researchers on one of the case studies who provided additional investigator triangulation.

Data are organised into case study databases, both of the raw data and of the interpretation or reporting of the data. The raw data will include copies of documents, newspaper reports and other published evidence, notes from observations and transcripts of interviews.

In this case, each case study will combine documentary evidence, with observation and data from interviews of participants and health service managers and clinicians. The interviews are central to the case studies, providing opportunities to explore in depth issues and values that may not be explicit in documents and may only be hinted at in meetings.

The aim of each study is to gain understanding of public involvement in health service decisions in a particular context. The results, while not universally generalisable will provide insights into the process of public involvement in the particular settings and will contribute to the overall understanding of how public involvement is undertaken in health communities.

The case studies are presented in a narrative form. This refers not to a particular methodology I employ, but to my approach to the presentation of

the evidence. I wanted, in each case to tell the story of how public involvement happened in that example. Each contribution from the interviews provided a particular perspective on the story and provided evidence that could aid with the understanding of the overall narrative.

4.4 Ethical Considerations

Although few would argue that research should not abide by ethical standards, it is more problematic to identify appropriate standards for specific research. In the health field, a new system of ethical review of research was instituted by the Department of Health in 2001. Under this review, all research that involved patients, carers or NHS staff was to go through the ethical approval process of Local Research Ethics Committees (Department of Health, 2001). When the new system was implemented, the survey of health authorities had already taken place and one of the case studies was underway, however for the case studies of service user involvement and community involvement, the agreement of LRECs was sought and obtained. This process delayed, but did not otherwise disadvantage the research resulting only in re-writing the informant information sheets and initiating a process for recording consent to satisfy the codified notions of ethical research standards.

There has been a long running debate about the ability of LRECs to comment on social research, particularly that which originates outside of the positivist paradigm (Oddens & De Weid, 1995; Dolan, 1999; Ramcharan & Cutliffe, 2001; Kent et al, 2002). Ramcharan & Cutliffe (2001) consider that the discourses of medical research ethics and social research are divergent and that the links between ethical review processes and medical research disadvantage qualitative methodologies. Christakis (1992) asks more fundamental questions about the ability of research ethics committees to adequately examine proposals that are based in alternative paradigms or rooted in minority cultures. These

concerns remain even though Committees now include broader representation than hitherto (Tod et al, 2002) and may result equally in both the approval of poor quality research or the delay and/or rejection of important and well designed projects.

Outside the health sector in the UK, there are no widespread formal processes for ethical review of social research, but researchers can be expected to adopt self-regulation based on professional standards. The Social Research Association (2003) considers that the imposition of rigid standards is incompatible with innovative social research, so approaches research ethics from a different standpoint, proposing an approach that addresses issues of professional integrity and responsibilities to participants through:

> *"...a framework within which the conscientious social researcher should, for the most part, be able to work comfortably. Where departures from the framework of principles are contemplated, they should be the result of deliberation rather than of ignorance."* (Social Research Association, 2003 p10)

Their framework includes obligations to society to maintain high standards and to disseminate findings to the benefit of society, to funders and employers, to colleagues and to subjects. The obligation to the subject of research is concerned with protection from harm and exploitation of individuals resulting from participation in the research and with informed consent.

Although slightly different processes applied, in undertaking all parts of the research, I adopted a very similar approach. All individual participants were invited to take part in the research and informed as far as possible on the overall aims of the research and their part in it. Where observational techniques were used, this was not feasible, but those organising events were informed of my intention to use the results of observation in this research. For those who participated in the interviews

and focus groups, they were made aware that their words may be used verbatim in reports, but assured that their names would not be used. In the reporting and analysis of the interviews and focus groups, only first names have been used and these have been altered to protect confidentiality.

Reporting the case studies also raises some ethical issues with respect to confidentiality. Despite changing the names used to identify individuals, by naming organisations and citing roles within organisations, there are some people who will in effect be identified. Although I considered the option of changing the name of organisations to avoid this inadvertent identification, this would not have been effective as each of the case studies has unique aspects which are important to the public involvement process and would reveal the real organisation in question. This is the case, for example in Knowle West, the Health Park was a unique development and in Somerset which was the first area to bring together health and social services in a single organisation for delivery of services for people with mental health problems. Although the argument is not quite the same with respect to North Bristol, there are unique issues with the state of hospital provision in the City of Bristol, including its relationship to the Kennedy Inquiry (2002) that would have made anonymising the organisation problematic for the research.

Chapter 5: A survey of health authorities

5.0 Introduction

At the beginning of this research there were few published national surveys of public involvement in health authority decision making, despite the continuing emphasis in government policies since the publication of "Local Voices" (NHS Management Executive, 1992). So, by surveying health authorities, I hoped to establish the extent to which health authorities in England and Wales were undertaking public involvement, how they were doing it, how successful they were in achieving involvement and whether and how they were including local views in their decision-making.

The survey was essentially descriptive, but from the responses, I hoped to be able to identify factors related to successful public involvement and to identify areas for more in-depth research. As a vehicle for research into the impact of policy, the mail survey is in reality inadequate. Although it can provide a certain level of data for the investigation of social phenomena, it is unable to collect information of sufficient depth about the motivations and priorities of individuals or organisations for a full examination of public involvement in health service decision-making (Robson, 2002). However by collecting a reasonably standardised set of data, I felt that I would be able to identify areas for further investigation and provide a snapshot of the development of public involvement at a local level. Following on from the survey, short follow-up interviews were undertaken with respondents from eight health authorities. More than twenty authorities also provided published material concerning their public involvement work. These included strategic documents, evaluation studies and reports of activity which had been presented to the Authority Board. These publications and interviews provided information to

contribute to the understanding of the state of public involvement and have been used in conjunction with the survey responses.

There were two areas of investigation for the survey, what steps health authorities were taking to involve local people and whether the involvement, when it happened, made a difference to decisions or to the process of decision-making. My work and the literature (Bowie et al, 1995; Layzell, 1994; Milewa & Valentine, 1996; Shepherd, 1995) led me to believe that there was progress in developing public involvement at a local level, but that development was patchy. This was a similar conclusion to that of the 1994 Department of Health survey which identified a range of activities and experience (Cooper et al, 1995). The Department of Health survey was carried out as a means of monitoring the development of the Local Voices policy. The assessment criteria were not made public and defining performance in developing public involvement policy would be difficult in my survey as there were no agreed standards. However, the College of Health had developed an organisational checklist for guiding the policies of health organisations (Kelson, 1997). The checklist covers steps to be taken in preparation for involving local people (although the College favours the term "users") in decision-making. These include:

- A written strategy;
- A separate budget devoted to involvement;
- Defined structures and processes and dedicated staff;
- A demonstrable commitment;
- On-going programmes of involvement, rather than one-off projects;
- Maintained contact lists;
- Local liaison and joint working with other statutory authorities;
- Complementary initiatives forming a coherent programme;
- Appropriate training for staff and users, including...
- Training from users for health professionals.

As the survey covered many of these areas, an assessment of the progress made by health authorities based on this guidance would be possible.

One of the few detailed surveys relating to public involvement in health authorities available at the time of the survey was Oberman & Tolley's work on priority setting in health authorities (1997). It was intended to examine priority setting activities, including the public's role, in health authorities. One of the main inspirations for this activity was the development of the Oregon Health Plan (Ham, 1998), in which the State of Oregon had attempted to engage the public in determining possible approaches to reform of Medicaid, the United States' programme for low income access to health care.

While Obermann & Tolley's survey covered only part of the involvement agenda, it was broad in its definition of involvement, including all contact between those forming policy and the wider community. The most common form identified was the formal and statutory consultation through CHC scrutiny. They also suggest *"There is a strong commitment to involve the public in one form or another."* (Obermann & Tolley, 1997: p. 13), but find there are practical difficulties including defining the relevant public, weighting public views against those of professionals and other forms of evidence and ensuring choosing between conflicting public views.

The survey provides an indication of the perceived importance of different criteria in setting priorities - and the roles played in priority setting by professionals, managers and the public. It was a finding of the study that involvement in "...*very technical services like intensive care or clinical scientific and diagnostic services"* (Obermann & Tolley, 1997: p. 10) was less likely than in community based services or those for people with long term conditions. Although they do not discuss this particular point, it raises the question of why this might be. For health services, the rationale

may be that public views are expected to be less informed about the more technical services, so that the "best" decisions are likely to be the result of expert discussion. In the case of long term services, those who use the services are likely to be well-informed and knowledgeable and have more of a contribution to make. This rationalist approach mirrors the traditional, technical model of health service decision-making in which certain types of knowledge, such as empirical evidence tend to be rated as more valuable than others, such as the views and opinions of service users or the public. However, what Obermann and Tolley do not acknowledge is that public involvement plays not only a role in rational decision-making, but may also represent a right of citizenship and represent a process of accountability.

I sought to go further than this earlier survey, to uncover what overall role public involvement played in health service decisions.

5.1 The survey questionnaire

The questionnaire was divided into four parts:

- The organisational context, describing the staff an structures established for undertaking public involvement;
- Public involvement activities undertaken by the Authority;
- The impact of involvement, an assessment to be made by the respondent;
- A range of other public involvement issues, including joint working with other organisations and the resources devoted to involvement;

The organisational context

It was important to establish where public involvement fit into the organisation of the authority, in terms of which department, if any, took the

lead, at what level responsibility was held and what action had been taken to establish structures and processes to build public involvement into the decision making of the authority.

Related questions in this section include; discussion of public involvement at Board meetings, strategic developments such as policies requiring Board level approval, the day-to-day organisation of public involvement and who participates in meetings and programmes of work with local people.

While most of these questions asked respondents to tick boxes, they were also asked to describe the process used to develop any statements of principles for decision making and public involvement policies or strategy.

Public involvement activities

The next section asked respondents to identify which of a number of common activities and techniques were being used in their authority. Each activity was given a brief description to aid classification.

Respondents were also asked whether they had offered training to those taking part in these activities and to describe what training had been undertaken.

The impact of involvement

The next section asked for an assessment on the impact of public involvement on specific plans or areas of work. The areas of work were chosen to include examples of the whole range of health service planning activities. Acute services and community were included, as was the range from very specialist to general services.

Respondents were asked to assess the impact of involvement on a scale of 1 (least influence on decisions) to 5 (most influence). They were also asked, for one of the services assessed, to describe briefly how public views were included in the decision making process.

Other issues in public involvement

This final section brought together a number of other relevant issues, including questions about work with other agencies, about the resources devoted to public involvement and about evaluation of initiatives.

An opportunity for further comments was added, as was an opportunity to express interest in participating in further work.

5.2 Data preparation

When the responses were received, they were entered into PinPoint for Windows software (Cole, 1996). Initial summary analysis was done in PinPoint, with more detailed analysis done in SPSS for Windows (SPSS, 1999).

Responses to questions requiring detailed written answers were grouped into identifiable themes and coded to facilitate analysis. These included the questions about processes undertaken to develop policy and to make specific decisions.

A "College of Health" (COH) rating was also determined. The rating was constructed as a score based on the organisational checklist from the publication "User Involvement: a guide to effective user involvement strategies in the NHS" (Kelson, 1997). Authorities were assigned one point for each of these guidelines that their responses indicated they currently had acted on. The effective maximum score was eight, as two of

the guidelines, the existence of contact lists and availability of user-led training for health professionals were not covered by the survey.

5.3 Results

Response Rate

The overall response rate for the survey was exceptional, at 91 per cent, with 2 Health Authorities declining to complete the questionnaire on the grounds of workload. The maximum number of non-responders from a single Region was 2, in Anglia and Oxford, Northern and Yorkshire and West Midlands.

Table 5.1: Response Rate by NHS Executive Regional Office

Regional Office	Returned	Sent	Percentage
Anglia & Oxford	7	9	78%
North Thames	14	14	100%
North West	15	16	94%
Northern & Yorkshire	12	14	86%
South Thames*	11	12	92%
South & West	11	12	92%
Trent	11	11	100%
Wales (Welsh Office)	5	5	100%
West Midlands*	10	12	83%
England & Wales	96	105	91%

* One refusal in each of these Regions due to pressure of work.

Organisational Issues

Leadership of Public Involvement

There is a notable lack of consistency in the lead department for public involvement, however in most health authorities, a lead had been determined and in 12/90 (13.3 per cent) a Directorate concentrating on public involvement, community affairs or similar had been established. The table below shows the distribution found.

Table 5.2: Organisation of Public involvement: Lead Directorate

Lead Department/Directorate	Number of Health Authorities	Percentage
Chief Executive	10	11.1%
Corporate Management/Services	11	12.2%
Strategy/Public Health	15	16.7%
Commissioning/ Quality	12	13.3%
Communications/PR	17	18.9%
Public Involvement/ Community Affairs	12	13.3%
No Lead Dept.	10	11.1%

In 60 per cent (54/90) authorities, the public involvement lead was at Director level, in 10 of these, it was the Chief Executive taking responsibility. Of the remainder, responsibility was at senior manager level, except for the 10 per cent (9/90) cases where there was no lead individual.

Numbers tend to be small, however there were some indications of the significance of the lead directorate. Where a directorate had been established with a remit for public involvement, community affairs or community development, it was significantly *more likely* that there would

be a defined annual budget (χ^2=4.03, p=0.044, Yates correction for small frequencies). In these Authorities, it was also more likely in these cases that training would be undertaken by staff participating (χ^2=4.89, p=0.027).

Where the lead Directorate was Strategy or Public Health, there was *less likely* to be a strategy on public involvement. Only 1/17 (6 per cent) of Health Authorities where the Strategy or Public Health Directorate was cited as the lead had an approved Strategy (2 non-responders to this question among Strategy/Public Health led programmes).

The leadership of public involvement may be an indication of where health authorities see the issue in respect of their work. The rational/technical view (as illustrated by Obermann & Tolley (1997) survey) would probably lead to a Public Health or Strategy lead, input directly into service agreements would imply a Commissioning lead and a Communications lead might mean that public involvement is seen as a public relations issue.

Values and Strategies

Fifty-six percent (50/89) of Health Authorities had developed core principles or values, which guide their decision-making. A further 29 per cent (25/85) were in the process of developing values or principles.

Fifty-two respondents reported on the process used to develop their values or principles. Of those who reported on the process, 78 per cent (38/52) had used an entirely internal process, involving mainly managers and directors. A few mentioned that the CHC and GPs, had been involved at some stage, but no attempt had been made to involve the public at large.

The remaining 27 per cent (14/52) had used a process which included a range of interests, including the general public and other stakeholders. There were a number of models in evidence, including surveys, focus groups, use of citizens' panels and stakeholder events.

Authorities were then asked whether the Health Authority had approved a strategic statement on public involvement. This was the case in 42/93 (45.2 per cent) of Health Authorities, while in a further 41/93 (44.1 per cent) there was an intention to develop a strategy or development was underway. Authorities, which had established values or principles, were *more likely* to also develop a strategy (χ^2=20.18, p<0.000).

The process used in developing a strategy was described by 53 Health Authorities. Most of these (30/53, 56.6 per cent) had developed their strategy with the involvement of the wider population.

Two health authorities sent their strategy papers with their survey responses. Bradford HA (1998) stressed the preparation of the health authority for undertaking public involvement work. They note the importance of internal champions, education and training and an interagency approach. In Avon, my home health authority, the "Public Involvement Statement" stated that *"All people have the right to be involved as individuals in decisions about their health (and)...participate in broader decisions as citizens."* (Avon HA, 1998: p.1). Additionally, the Authority required quarterly reports on public involvement from the Chief Executive.

Committees and Groups

In more than half of all health authorities (49/92, 53.3 per cent), oversight or guidance of public involvement was the responsibility of an internal committee or group.

These groups invariably included senior managers. Executive Directors were also included in most groups (33/49, 67.3 per cent), however there was also a high level of CHC membership of such groups (38/49, 77.6 per cent). Other Health Authority staff (26/49, 53.1 per cent) and Non-executive Directors (22/49, 44.9 per cent) were also often involved. In 23 Authorities (46.9 per cent), other people were included in these groups. These most often included local authority staff or people from voluntary organisations. A very few Health Authorities had established broad-based forums for the discussion of public involvement in decision-making.

Participation in public involvement activities

Executive directors and senior managers were equally active in work with local people, being involved in this work in almost all health authorities. Chief Executives were slightly less often involved, while more than two-thirds involved Non-executives and the Chair of the Authority. One fifth involved people from outside the Health Authority. This included private sector consultants, academics and members of the CHC or local voluntary sector.

Table 5.3: Participation in public involvement activities

	Number	Percent
Chair of the Board	64	67.4%
Non-executive Dir.	67	70.5%
Chief Executive	80	84.2%
Executive Director	85	89.5%
Senior Managers	85	89.5%
Other HA staff	58	61.1%
Others	21	22.1%

5.4 Public Involvement Activities

Public involvement methods

All Health Authorities had experience of at least one of the public involvement activities included in the questionnaire. Most were employing a number of different methods. The least used of the those included were the deliberative approaches such as citizens' juries (6 per cent of health authorities) and health panels (22 per cent), which involve groups designed to represent the local population discussing and responding to specific questions or issues (Jordan et al, 1998; Bowie et al, 1995).

Smaller meetings, such as focus groups (82 per cent) and less structured meetings with health interest groups (78 per cent) were also common. These approaches are opportunistic and involve those who put themselves forward, often with a specific interest in the question or service under discussion. While this means that they are not statistically representative of the local population, participants do tend to have a level of knowledge about services.

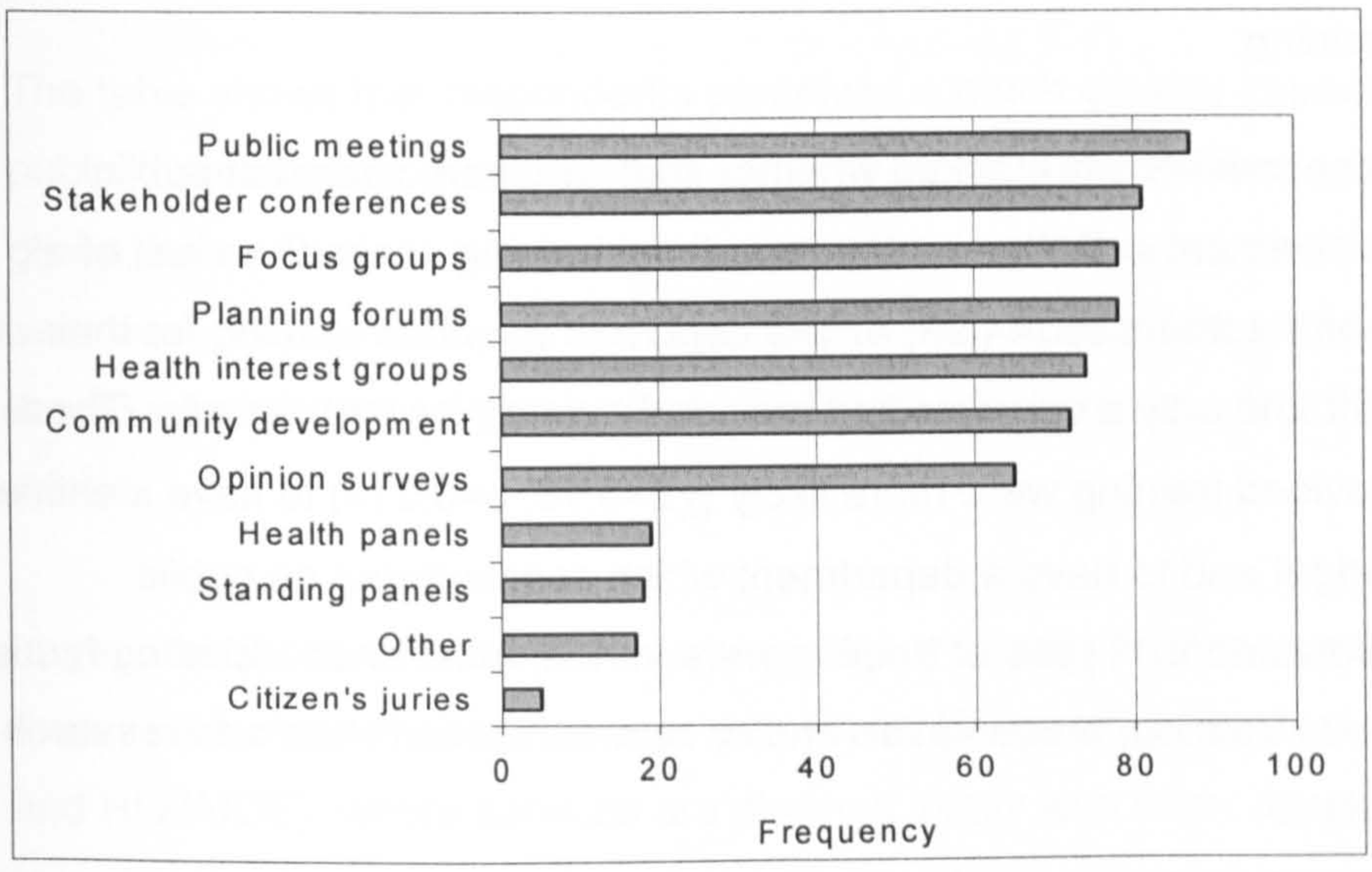


Figure 5.1: Methods used by health authorities in involving the public

Community development, is *"...a way of working, that is underpinned by core values and principles. It is about working* ***with*** *people, not for them and the focus is on collective activity rather than individual activity"* (original emphasis) (Sheffield HA, 1997: p. 2). While most health authorities (72/95, 76 per cent) said that they used community development methods, only in a very few (4/95, 4 per cent), was there evidence that it had been adopted as *the way of working* for the authority. The evidence came either from documents sent with the questionnaire, from the structures or training outlined or from responses to questions on public involvement processes.

Among the few health authorities that outlined other methods, the most commonly cited were rapid appraisal approaches to health needs assessment (Murray et al, 1994), search conferences, open space and other whole system approaches to planning.

Training

Respondents were asked whether staff who participated in public involvement activities had received any training. Less than half of all health authorities (44/93, 47 per cent) had provided training for their own staff and only a very few had provided training for participants. Those who provided training were more likely ($\chi 2=6.18$, $p=0.013$) to have identified a budget and to have a department which concentrated on public involvement. Types of training were varied, most often including focus group training, presentation and/or communication skills and research skills.

5.5 The impact of public involvement

The impact on specific planning decisions

Table 5.5 shows how many responses about public involvement in relation to different services. It shows that reviews of services were not evenly distributed across services, and that public involvement was more likely to have an impact in some services.

Table 5.5 Impact of involvement on different services

Service	Total Responses	Impact 4-5 (high)	Percent high
Oral health	26	6	23%
Community nursing	21	5	24%
Family planning	32	9	28%
Emergency admissions	24	7	29%
Elderly services	46	17	37%
Accident & emergency	37	14	38%
Elective surgery	23	9	39%
Cancer	52	22	42%
Diabetes	32	15	47%
HIV/AIDS	38	20	53%
Health promotion	30	16	53%
Closure of a hospital	51	28	55%
Physical disability	43	24	56%
Maternity	58	33	57%
Learning difficulties	46	28	61%
Mental health	68	44	65%

The table shows that respondents perceived a much greater impact of public involvement on decisions in some services than in others. As a group, those services where high impact of involvement was above 50 per cent were mentioned by an average of 48 Health Authorities, compared to the 33 who mentioned those where the high impact was less than 50 per cent.

In general, those where there has been higher impact are those where there is a history of a service user movement (for example in mental health and HIV/AIDS), where services are planned jointly with other agencies (mostly social services) and where multi-disciplinary planning groups have been introduced. Exceptions are where other influences have come into play. For example, some responses on maternity services specifically mentioned the existence of Maternity Services Liaison Committees, with lay membership as influential. In the case of hospital closures, the emotive nature of these debates tends also to mean that they are taken up by local politicians and media, often developing in an atmosphere of confrontation, which can lead to resentment on both sides.

The process of involvement

Respondents were asked to describe the process for including the views of the public in one of the decisions reported on in the previous question. Some health authorities did not answer this question, however a total of 70 responded sufficiently to classify the process into one of four groups.

The largest group (45 health authorities) described an indirect two-stage process in which the views were gathered by various methods, then summarised in a written or verbal presentation made at the Board meeting. This can be seen as a development of the "traditional" consultation process, although the approaches employed for gathering the

views of participants were often innovative, including citizens' juries and health panels.

The second group (18 health authorities) described setting up an on-going structure such as a user group or reference group, involving the public or service users, and which participated in the preparation of the plans over a period of time, with a continuing role in monitoring the service or implementing the change after decisions had been arrived at. This is more of a direct form of involvement which brings participants into contact with those who make the decisions and may enable a deeper understanding of the views of service users or citizens on the issues concerned. However, the number of people likely to be involved in such groups will inevitably be small and all perspectives may not be included in discussions.

The third and fourth groups were much smaller, in the third group of four health authorities, involvement and the decision-making seems to have taken place simultaneously, for example in a "whole systems" event which decided local policy, then ratified by the Authority. While this can be seen as a variant of the traditional approach, it condenses the process so that participants can make more of a contribution to the development of plans. Whilst it may seem that this represents, in Arnstein's (1969) terms a decision-making partnership, it was not clear how the process worked, whether all views were represented or whether the Authority would consider revising the decisions of the event.

Finally, there were three instances where a process was described in which the health authority's decision was challenged, with the decision overturned by the Secretary of State. This represents the conflict model in which the public's views are strongly opposed to those of the health authority. Comment from respondents suggested a continued bitterness over the decision process. Follow up work with one of these health

authorities in South West England indicated that it had had a significant impact on the planning process, leading to a re-evaluation of their approach and development of a community focused system (Trisha, Locality Manager, follow-up interview).

5.6 Other Public Involvement Issues

Joint working

Almost all health authorities participated in joint work on public involvement with other organisations. The most common partnerships were with the CHC and voluntary sector umbrella groups, with local authorities and NHS Trusts also common partners. The proportion of Authorities involving different agencies is shown in table 5.6.

Table 5.6: Involvement of other agencies in partnership work

Organisation	Number of Health Auth.	Per cent
Community Health Council	91	96%
Voluntary umbrella groups	87	92%
Social services	79	83%
NHS Trusts	76	80%
Primary care	68	72%
Other voluntary sector	58	61%
Other local government	57	60%
Academic institutions	43	45%
Private sector experts	33	35%
Professional organisations	31	33%
NHS Executive	27	28%
Others	6	6%

Budgets and Resources

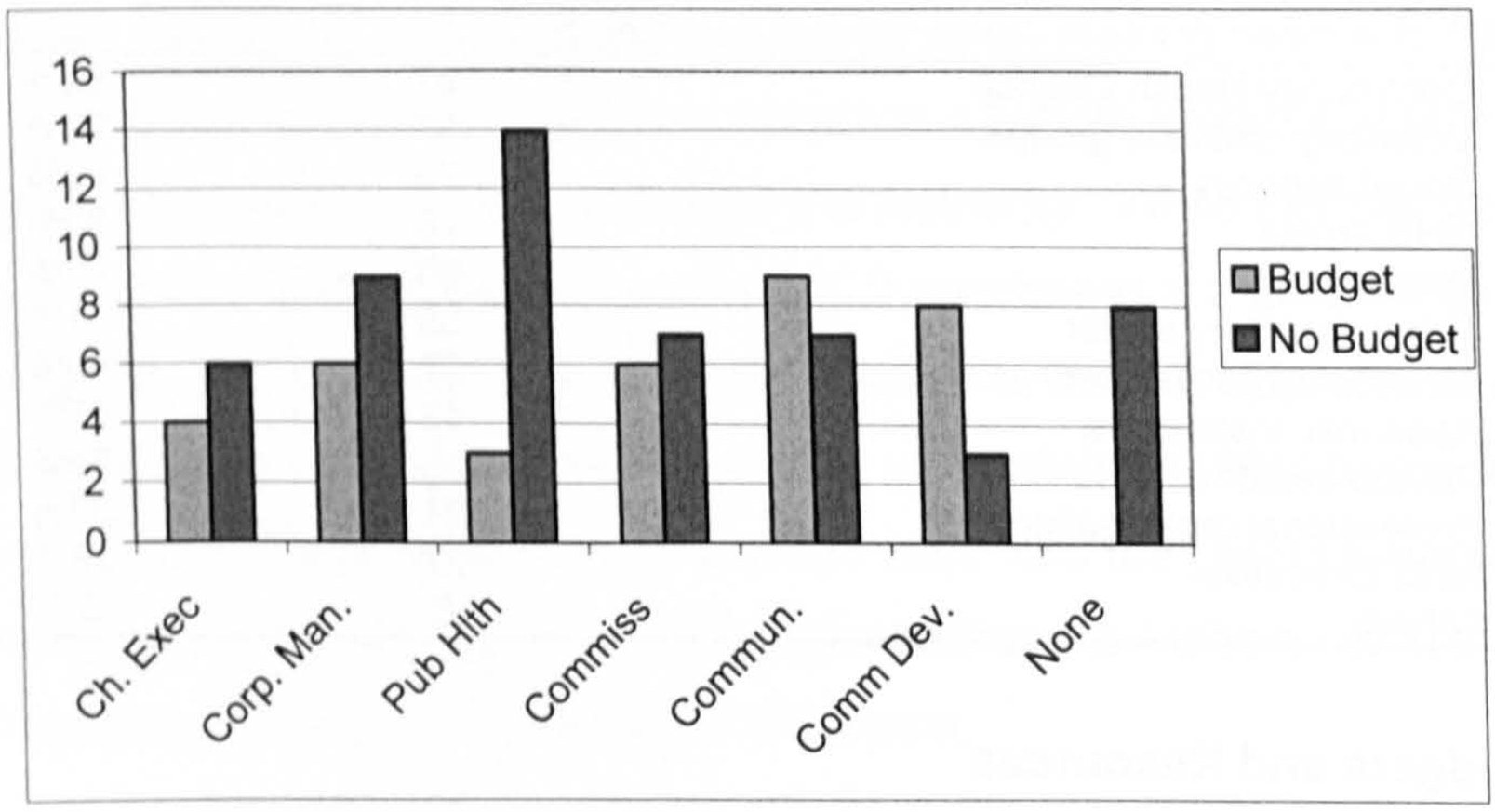
Authorities were asked whether they had a defined budget for public involvement work and if so, to specify the annual budget. Of the 80 respondents who answered this question, 46 (58 per cent) said that there was no budget identified. A few added that money was accessed as necessary from other budgets. Eight of the 34 (42 per cent) who were

able to identify a budget were not able (or unwilling to) specify the amount available.

The median amount for those who did quantify their public involvement budget was £24,000, however there were wide disparities. Two Authorities reported an annual budget in excess of £100,000, whereas almost all of the others were under £50,000.

Figure 5.2 compares setting public involvement budget with responsibility for undertaking the task. Most striking is that where the Public Health Department took responsibility, or where there was no overall lead, a budget was less likely. Defined budgets were most likely where the lead was taken by a department devoted to involvement or when the communications department took the lead.

Figure 5.2: Budget and responsibility for public involvement



Evaluation

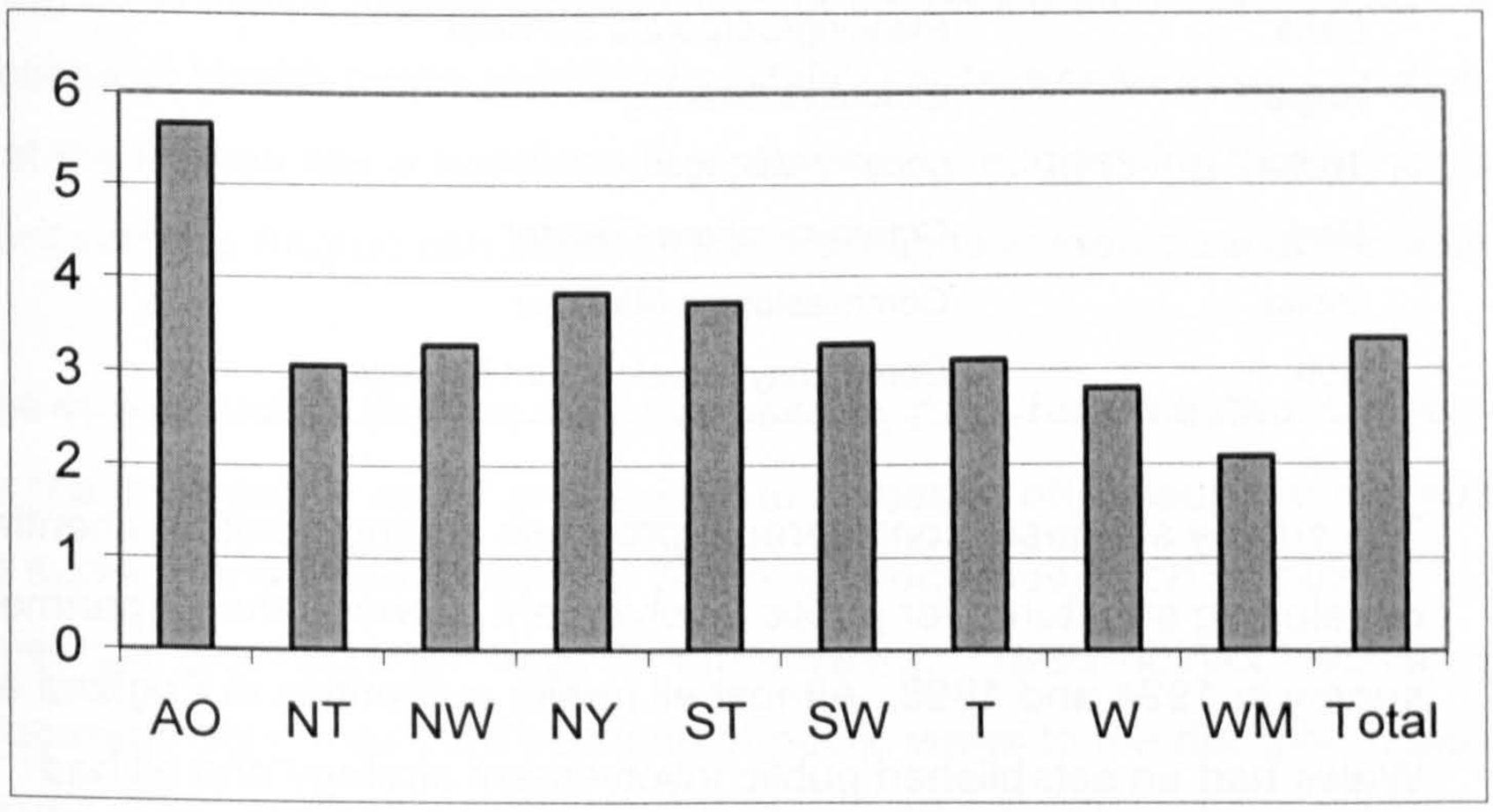
Evaluation of public involvement activities had been undertaken in 36.1 per cent (33/89) of Health authorities. Most of the evaluation reports sent with responses referred to single events or activities such as a stakeholder

event or a series of health panel meetings. The exception was the Anglia and Oxford Region, where a peer review process existed for programmes of public involvement. Reports of peer review assessments were collected from several authorities in this region, these show that Authorities were sharing their practice and working together across boundaries.

College of Health Rating

Responses were assessed for performance against the College of Health checklist (Kelson,1997). Scores ranged from 1 to a maximum of 8, with a mean score of 3.32 (standard deviation 1.8). Figure 5.3 shows mean scores by Region. Anglia and Oxford show a mean score significantly higher than the other Regions (One-way ANOVA, F=5.08, p=0.000)

Figure 5.3: College of Health rating by Region



Key:

AO – Anglia & Oxford
NT – North Thames
NW – North West
NY – Northern & Yorkshire
ST – South Thames
SW – South & West
T – Trent
W – Wales
WM – West Midlands

5.7 Follow up work: Interviews and analysis of reports

In the covering letter sent with the survey, Health Authorities were requested to send any relevant reports or other documents that would add to their responses. I collected relevant documents from more than 20 of the Authorities. Additionally, following up the survey, I undertook eight short interviews of respondents, chosen to provide views from a range of health authorities. The interviews were predominantly face-to-face, although two were conducted on the telephone. Interviews were recorded and transcribed for analysis. A list of interviewees, together with their role in the health authority is given in Table 5.7

Table 5.7: Follow up interviews

Name used in text	Role
Nicky	Communications Manager
Cerys	Health promotion Manager
Delia	Planning/Corporate Services
Angie	Executive Director
Trisha	Locality Manager
Mark	Communications Director
David	Commissioning Manager
Bob	Community Development Manager

The survey suggests considerable progress among health authorities in developing structures for public involvement between the Department survey in 1994 and 1998. Almost all health authorities in England and Wales had an established public involvement strategy and all had undertaken some work in this area. However fewer than half had established a budget for the work and only 13 per cent had a department specifically devoted to engaging the public. These figures suggest that public involvement remained peripheral to the work of the health authority. A similar conclusion is reached by Rhodes and Nocon (1998) who question the development of "user involvement" in the reforms of the late

1990s, despite the continued growth of user groups and a number of initiatives from government over a long period (Department of Health, 1997;1998; NHS Management Executive, 1992; NHS Executive, 1995;1996;1997).

Further evidence for the failure to establish public involvement as a central issue for health authorities comes from the responses to the question about the involvement of other organisations. While for most policy issues, the NHS Executive was a central influence at the time, there was little involvement of the Executive in the development of public involvement policy, this despite the inclusion of the issue as one of the key planning targets for 1995/96 (NHS Executive, 1995). Again, the exception was in the Anglia and Oxford Region, where the peer review process may have had a role in developing the approach of the health authorities in the region. Sample reports show that the peer review process included an analysis of the structures and activities of the health authority. Using the College of Health Score (admittedly a fairly crude measure) we can see that the Region has a significantly higher rating, suggesting that concerted work within a Region can improve the processes in individual authorities.

The survey shows that the methods used by most health authorities were, for the most part, indirect and tended to be based on research tools, such as surveys and focus groups, or planning processes, such as public meetings, that had been used for many years. These indirect involvement processes bring mediated versions of public views to the decision-making forum. They can be seen as an extension of the traditional consultation process, in which control remains firmly in the hands of the health authority. Even where user groups were incorporated into the decision-making process, they remained at arm's length from the decision-making forum, with the mechanism for inclusion some form of reporting to decision-makers. Only in a few authorities had used more innovative approaches, including "whole systems" events, where decision-making

and involvement apparently took place simultaneously. While joint planning processes also involved the voluntary sector and service users, these interestingly, were not described by any survey respondents as processes for public involvement.

From both survey responses and from subsequent discussions with respondents, there was evidence that involvement was taking place at different levels in health authorities across the country. For example, a report from South Humber Health Authority (1998) reported on a project to involve people in a "consultation" process about the future of health services in general in the area. The study found that there was scepticism among local people of the motivation for the proposals, people believed that change was more likely to be aimed at reducing costs than improving services(South Humber HA, 1998). It also found that the authority sought not to involve the public in their decisions, but to explain decisions that had been made. On the other hand, local people sought not to be able to make the decisions, but *"...to request issues to be raised"*. (South Humber HA, 1998 p.40)

In Daventry Primary Care Group, a patient panel had been established using survey techniques (Daventry Purchasing Agency, 1998). The panel, a representative sample of 103 people were questioned about the issues to be brought before the PCG Board with the aim of providing a broader contribution to the debate at the PCG. In the evaluation, GPs expressed surprise about *"...the ability of the lay people to understand the business of the NHS"* (p. 14) and noted that it represented the end of *"...the era of doing things behind closed doors"* (p.15). On the other hand, participants in the panel were not so sure. Although they agreed that it *"...raised the veil of secrecy...from NHS funding"* (p. 24) some were not sure that their contributions were valued by the PCG *"...I have the niggling feeling that the panel is there so the health authority can say it has involved the public..."* (p. 26).

Although any definition of success in public involvement will be arguable, the survey provides evidence of where health authorities had made concerted efforts to develop appropriate processes for involving local people. Identifying a budget for the work and appointing officers at a senior level appear to be two of the most important steps taken.

The high level of response, however indicates that all health authorities recognised this as an area of importance to their role at a local level, while the lack of involvement of Regional Offices of the NHS Executive shows that it lacked the impetus as a policy theme at the national level despite the inclusion of patient and public involvement as one of the top priorities for the NHS (NHS Executive, 1995). Where, in Anglia and Oxford, Regional interest was demonstrated, the result was the sharing of good practice across health authorities.

Much of the commitment appears to be rhetorical, for while for example Southampton and South West Hants HA say *"If high quality...services are to be developed, there has to be a commitment to enhance the involvement of users"* (Southampton & South West Hants HA, 1997: p. 1), there is precious little evidence either there or in any other health authority that the views of service users were connected to service change. Nor was there much evidence that service managers put public involvement high on the agenda. In follow-up interviews, one lead officer told me

> *"...actually we don't get that commitment from some of the directorates. It (the public involvement steering group) is not an important group in the organisation – meets quarterly, but not well supported. It's always left to a few enthusiasts to keep it going. That's not to say the others aren't interested, they are but other things are always more pressing, higher priority"* (Nicky, Communications Manager; follow up interview)

In another health authority, cancer service users were involved in assessing the quality of services. The assessment of service users was that there was little to criticise in the services or treatment, but there was significant criticism of the modes of delivery, the way in which people were

treated and how decisions were made by clinicians. Specific criticisms concerned communication between professionals and patients, privacy and sensitivity in relationships between clinicians and patients and the issue of the emotional well-being of patients (Southampton & South West Hants HA, 1997).

Among participants in programmes of public involvement, there was recognition, even an expectation of this attitude. Their view seems to have been that the process was neither open, nor engaged in with integrity nor likely to lead to change. In South Humber for example, a programme of consultation was undertaken by an independent consultant to gather public views of major strategic change. Although there was some support for some proposals, there was also a feeling that the real motivations were financial, rather than the service quality highlighted in documents:

> *"...the drive for change is one of cost reduction rather than enhancement of quality of service delivery"* (participant 1 quoted in South Humber HA, 1998: p. 8)

> *"...the emphasis has been on explaining what the changes are rather than the consequences"* (participant 2 quoted in South Humber HA, 1998: p. 8)

In the Bristol area, a review in 1993 had used a focus group like approach to gather information at an early stage, when proposals were in development. The Person-to-Person project (Burton, 1994; Shepherd, 1995) provided indirect contributions from more than 30 groups over a six month period. However although this represented a considerable investment for the health authority, in staff training, in supporting groups to enable them to hold meetings and in terms of managers' time, the resulting review document used the contributions *only* as captions for the illustrations. All proposals were justified with reference to health service produced data and the opinions of experts (Bristol & District HA, 1993).

In some areas, however the accepted model of working was community development and the value placed on public involvement appeared to be greater. This was particularly noticeable in health action zones (HAZ). At this time, HAZs were early in their development, but they were created early in the first term of the Blair government with the aim of tackling health inequalities through a range of innovative approaches. In Plymouth for example, the HAZ was committed to involving service users in decision making forums. In all, thirteen areas of policy were led by decision-making groups that included service users or local people. In mental health, service users made up the majority of the group (Plymouth HAZ, 2001). In the neighbouring Cornwall HAZ, policy making was more decentralised, with involvement being in the day-to-day running of programmes, including community development initiatives (Trisha, Locality Manager: follow-up interview).

Those managers who demonstrated a commitment to community development principles were more passionate about the importance of demonstrating the relationship between involvement and decisions and less convinced that indirect methods would be sufficient. A health promotion manager told me that there has to be:

> "(some) *sort of real commitment about where this information goes, what impact will it have for them, who is going to come back and disseminate it back to them, can they be kept informed…That it is not a report that is produced at the end of the day just for the Health Authority board…(It) feels like there should be a real…contract or a memorandum of agreement…So its about 'If we take part in these consultations, or if we give you feedback, in what way is this going to influence your decision-making as a local organisation or actually is it already sewn up and this is tokenistic?' So it is about what the process is, what the outcomes are and in what way are the outcomes going to be influenced by local people's direct involvement or contribution* (Cerys, Health Promotion Manager: follow up interview)

The assessment of the impact of involvement provided intriguing results. Although this was only a personal view of the impact, without for example considering what those involved thought or the final decision, there

appeared to be more impact where there was an existing user movement, such as in mental health services, or a formal mechanism for involvement such as in maternity services. Obermann & Tolley (1997) refer to *"more technical services"* (p. 10), as associated with less involvement, however neither elderly services nor community nursing can be described in this way, but impact in both was assessed as limited. It may be that the importance of the user movement is in developing a level of expertise among participants that makes their involvement more likely to alter thinking in the health authority or which health authorities are more likely to encounter in developing policies. Another possibility is that it is in these services that the power of medicine is least likely to assert itself, perhaps because the influence of other forces such as local authority involvement or government policy is stronger or because these services are not seen by medical organisations as central to their interests. These issues are far more difficult to tackle through survey research, but further insights may be gained through qualitative approaches used in the case studies

5.8 Summary

The survey makes a major contribution to the development of this research. It has demonstrated that at a time when public involvement had been consistently promoted by national policy for more than five years, in very few had it changed the policy process fundamentally. For the most part it appeared to be a bolt-on process that was a minor influence in comparison to those of clinicians, national policy makers and local managers. The survey also identified a number of themes to explore in more depth through case studies, including the importance of existing user movements, the role of national policy in legitimating local activity and the importance of commitment of resources and preparation for involvement through establishing values and strategies

Chapter 6: "Getting our point across": Involvement in strategic decisions

6.0 Introduction

North Bristol NHS Trust is the biggest NHS Trust in the South West, employing 9,500 staff and serving a local population of about 500,000. It was formed by the merger of two former NHS Trusts in 1999. The Trust now runs seven hospitals, including two major District General Hospitals at Southmead and Frenchay, north of Bristol's city centre. These both provide a full range of acute care for local populations. Each one also provides more specialist care for patients from a wider area.

The merger was not an easy one, a Commission for Health Improvement Report referred to *"two different cultures"* and an inability to *"integrate clinically and culturally"* (Commission for Health Improvement, 2002 p. xii). There was also a view among senior staff that the new Trust could not sustain two hospitals, both now aging, in poor repair, close together and to an extent duplicating services. Among senior medical staff it was seen as an opportunity to improve the quality of facilities to become a leading edge provider of care by building a new hospital.

The recent history of hospital care in Bristol is important to understanding this case study. There have been three major hospitals in the City which have shared the provision of acute health services to a local population of about 750,000. Specialist services have been located in all three, with local and regional health service planners seeking to minimise duplication of specialisms. In the late eighties for example, this led to the development of the "Avon Orthopaedic Centre" at Southmead Hospital to centralise orthopaedic surgery, while at Frenchay Hospital, a specialist head injury centre was established. To an extent, these corporatist planning approaches were thrown into disarray by the 1990 reforms and

the purchaser-provider split. The emphasis on autonomous organisations of providers of care put the three hospitals into competition with one another. All became NHS Trusts, providing all hospital and community healthcare, but dominated by their acute hospitals. In a sense, this solidified an existing situation as within the comparatively small area around Bristol, there had always been something of a competition for reputation among the three. The third hospital, actually a group of specialist hospitals, in Bristol is in the centre of the City and run by the United Bristol Healthcare Trust (UBHT). This group, centred on the Bristol Royal Infirmary (BRI), one of the longest established hospitals in the UK, has historically had much better links to the University medical school, to which it is adjacent, and has tended to attract more attention than its two neighbours to the north. It has also attracted more high profile, research funding, had a higher reputation as a national leader in hospital care, and been seen as the premier institution for healthcare provision in Bristol.

The years around the turn of the century were very difficult ones for the BRI. As a result of the scandal that followed the deaths of children undergoing complex heart surgery, two senior surgeons and the Chief Executive were disciplined by the BMA and a public inquiry, the Kennedy Inquiry (Kennedy, 2001) was established to investigate not only the circumstances under which the deaths had happened, but the whole organisation and its culture. The Inquiry concluded that this was a systemic, rather than an individual failure that was borne out of the culture of the organisation and its attitude to change and criticism. Kennedy recommended changes not only within the Trust, but throughout the health service (Smith, 2001). The reputation of the BRI was severely damaged by the whole process. And though it would be wrong to see the proposed developments in north Bristol as a consequence, the senior medical staff, now working in a single merged organisation, identified an opportunity to develop a centre of excellence in health care in the area and pushed for

the development of a plan for replacing or re-building the hospitals in north Bristol.

Re-development would have a number of positive effects for North Bristol. It would address the deterioration in the facilities, all of which were in poor repair and need of renovation, it might finally bring the Trust together, not only in one hospital, but in terms of a single focused organisation and it would enable the medical staff to progress their view of the future of high tech medical care.

The Trust, guided largely by senior clinicians, had come to the view that the strongest case was for consolidation of the two current hospitals into one. This approach would enable efficient use of shared services like intensive care and radiology, would improve care and would minimise the need to transfer patients between hospitals. Underpinning the approach was the view that the trend for "minor" treatment to take place in primary care would continue and that local GPs and the Primary Care Trusts would work with the North Bristol Trust to develop appropriate services. In a leaflet published in the early summer of 2001 (Maidment, 2001), they set out this model and identified four possible ways forward: to upgrade of both hospitals to a minimum standard; to modernise one of the hospitals to a high standard, while closing the other or; to close both and build a new facility on another site. The Trust view was included in the leaflet, that the best solution was a new hospital on a new site.

The Trust Board embarked on a process of building up the business case and bidding for capital funding. This process, known as producing a Strategic Outline Case (SOC) was the first stage in the preparation for capital funding from either the Government or through a Private Finance Initiative (PFI).

In parallel to the discussion in the Trust, though beginning later, the local Health Authority had initiated a review of the provision of all services, based on the notion that most health care should be provided locally, with support from specialist hospital services. They had adopted a "model of care" that called for significant development of local facilities and a well-developed partnership between staff in all health care settings.

6.1 The Case Study

An early decision was taken by the Trust Board to "involve and consult" local people on their plans in advance of a formal decision on the future of its services was as required by the Department of Health under the NHS and Social Care Act (2001) and as required by the Strategic Outline Case process. This case study was designed to evaluate the quality of the work done by the Trust to involve local citizens and to assess the extent to which the strategy for involving local people was influential in determining the outcome of the Programme Board's work. As it turned out, the Board's work led not to a submission to the Department of Health, but into another process (which continues) to secure a future for health care across a wider area in what amounted to a return to the corporatist planning evident before the purchaser-provider split. The latter process began part way through the period covered by the evaluation and led to considerable confusion among many members of the public who participated in meetings and discussions sponsored by the Trust. They were not sure whether they were commenting on proposals from North Bristol Trust or the entire "health community".

The data for this case study was gathered from documents produced by and for the Programme Board, coverage of the debates in the local media, notes and observations at monthly Programme Board meetings between May and November, 2001 (North Bristol Trust, 2001a-j), observations at meetings held by the Trust to involve local people in the decision-making

and interviews with Programme Board members and members of the public involved in public meetings or focus groups. I had also run 12 focus groups on behalf of the Trust. These involved 108 local people, all of whom had also made comments to the Trust or otherwise made contact to discuss the proposals. The transcripts and report from these groups provide additional information for the study (Shepherd, 2001).

Interviews undertaken in the course of the case study included 10 managers or clinicians from the Trust's Programme Board and 8 local people. Interview participants were selected purposively to represent differing perspectives within the Programme Board and to ensure that participants from the range of approaches to involvement were included. Table 6.1 gives the names by which interviewees will be known in the text, together with their role at the time. In information provided to participants, they were told that in reports from the research, their names would not be used and this is the approach I have used to develop a measure of anonymity. For Programme Board members, there is a tricky ethical issue in that they are equally identifiable from their role. However in the analysis, it is equally important to relate their role in the local NHS to the comments they make in relation to the issues discussed, so although identification of individuals may be possible, I have nevertheless included their role in assigning quotes.

To progress the re-development of their facilities, the Trust had appointed a Programme Board, chaired by the Chief Executive and including representatives from the Trust, primary care, the local Health Authority, Unison and the Community Health Council. Although the membership of the Board may have the appearance of a partnership involving may of the stakeholders in health services in the area, the Chief Executive of one of the Primary Care Trusts (PCT) represented characterised it somewhat differently: *"...we were incorporated, rather than in a partnership role in the Programme Board"* (Charles). The implication that PCTs were very much

secondary to the process captures accurately the weight given to the "twin" aims of developing the hospital and community services in the proposals of the Trust.

Table 6.1: Interviews, North Bristol Trust Case Study

Name in text	Role
Clive	Planner, North Bristol Trust
Steven	Planning Director, NBT
Terry	Chief Executive, NBT
Jill	Communications Manager, NBT
Helen	Communications Manager, NBT
Richard	Medical Director, NBT
Jeremy	Director of Strategy/Acting Chief Executive, NBT
Charles	Chief Executive, Primary Care Trust
Alan	Strategic Director, Health Authority
Graham	Assistant Medical Director, NBT
Sally	Local resident, focus group participant
Owen	Local resident, meeting participant
Samuel	Local resident, focus group participant
Phyllis	Local resident, meeting participant
Walter	Local resident, correspondent
Dipak	Local resident, focus group participant
Isabel	Local resident, meeting participant
Ron	Local resident, focus group participant

Initially, the Director of Strategy, as acting Chief Executive chaired the meetings, however a new Chief Executive was appointed during the process and he chaired the later meetings of the Board. Subsequently, there was considerable change in other positions, as the Strategy Director, Planning Director and Finance Director soon left the Trust.

The Board agreed a "user involvement strategy" for guiding the involvement work. The strategy took the approach that there should be a

range of involvement opportunities, including public meetings, survey work and focus groups. It proposed an open invitation to local groups to invite the Trust to speak at their meetings or set up public meetings and for individuals to write in, email or telephone with comments. Additionally, the Trust aimed to use citizen panel surveys in Bristol and South Gloucestershire and sponsored 12 focus group discussions in various locations across their catchment area. I was asked by the Trust to conduct and analyse the focus groups. A "reference group", involving stakeholder groups, including the CHC and other representatives of the local voluntary sector is also noted in early meetings of the Programme Board. However, it is unclear whether this group ever actually met (none of those interviewed mentioned it and it was not mentioned in any Programme Board meetings that I attended).

When the process of consultation on the proposals was officially launched in July, 2001, the Bristol Evening Post reported

> *"Walk through the grounds of Southmead and Frenchay hospitals and it's not difficult to see why they fail to meet the needs of modern-day health care.*
>
> *Southmead has ageing Victorian buildings which are imposing, expensive to run and totally impractical for state-of-the-art medical equipment.*
>
> *At Frenchay, patients and staff still have to put up with brick-built nissen huts which date back to the Second World War, when the site was used as a US military hospital which specialised in treating burns victims.*
>
> *The hospitals are now run by the North Bristol NHS Trust, which wants to revolutionise health care in its area which stretches out to Yate, Thornbury, Clevedon and Kingswood.*
>
> *The jewel on the crown would be a £240 million state-of-the-art hospital to replace Southmead and Frenchay. It would be built on a 65-acre greenfield site – yet to be identified – on the northern fringe of the city."* (Onions, 2001a)

Although this was the official launch, considerable local debate was already taking place following earlier discussions of change in the local health service. Steve Webb, the Liberal Democrat MP for Northavon took a particular interest, expressing his concerns in a column in the Evening

Post (Webb, 2001). He also asked his office to conduct a survey of opinion within the constituency that makes up about a third of the Trust's area.

The survey was conducted well in advance of the Trust's own work. His office sent questionnaires to 40,000 local people. Responses were received from more than 5,000 people. The responses showed a clear preference for modernising both hospitals and developing local services, with two-thirds opposing a single site. Webb himself was quoted as commenting:

> *"The clear message from my survey is that people do not want large impersonal hospitals, but do want readily available health services"* (Steve Webb MP 2001 quoted in Bristol Observer, 03/08/01)

Among Programme Board members, the survey was viewed with some hostility. Some challenged the representativeness of the sample, response bias, or the conduct of the survey. It was described by one Trust Director as *"PR minded"* (Steven), one of the other Directors thought that the MP had *"jumped the gun"* (Richard) in deciding to survey constituents and that it *"posed a fairly stark question without giving any of the evidence or any of the alternatives"* (Richard). Others thought *"...it was a slightly biased approach..."* (Jeremy) and "*was purely political"* (Jill). However their expressed consensus was that the MP's intervention was not particularly influential in the Trust although it was credited with bringing the issue into the open by some citizens who took part and with stimulating the Trust action by at least one Programme Board member:

> *"The Trust recognised that it was high profile politically because of the interest that they had already had from the MPs...the survey from one of the MPs...was beginning to influence public opinion, so I think they did recognise that this was going to be a big political and public issue."* (Jeremy)

Despite the criticism of the conduct of the survey, the results appear to have been quite robust. The preference for the modernisation of both

Southmead and Frenchay among local residents was substantially replicated by the comments received, the Council surveys and the responses of those who attended focus groups (Maidment, 2001). The Trust's report on stakeholder involvement noted that of those writing in with comments and expressing a preference, 121 out of 176 (69%) people preferred that both hospitals should continue to provide services (Maidment, 2001).

6.2 Implementing the Involvement Strategy

The Trust sought to implement a comprehensive programme of stakeholder involvement from May 2001 (North Bristol NHS Trust, 2001a). The strategy identified "critical success factors" for achieving stakeholder involvement. These included "buy-in" from decision makers and *"Providing full and timely feedback to participants, including explanations of why decisions have been taken"* (North Bristol NHS Trust, 2001a: no page number). A cornerstone of the process according to the strategy was to keep people informed and the Trust began by distributing 175,000 leaflets to households in the area and establishing a database of responses to the proposals by mail and telephone. They also held meetings with voluntary and community groups, set up public meetings and collected information through questionnaires and focus groups.

Activity was already well under way by the press launch of the process of involvement in July 2001 and the numbers involved are impressive. Overall, the Trust was contacted by almost 1,200 people by mail or telephone. Trust managers attended more than 60 meetings in the local community and a similar number with Trust staff. In many of these, the issue of the redevelopment of health facilities was covered as a part of the host organisation's existing agenda, but other meetings were set up specifically to discuss the proposals. A questionnaire was circulated to members of the Bristol Citizens Panel and the South Gloucestershire

Viewpoint Panel who lived in the Trust area. These Panels are used by the Councils to gather local views on current issues. Participants are selected to be representative of the local populations in terms of age and sex, ethnicity and location. On this occasion, more than 2,400 questionnaires were distributed and over 1,400 returned for an overall response rate of 60%, with a slightly higher response rate among Bristol residents (Maidment, 2001).

The numbers involved and the number of meetings are an indication of the extent of the workload for the Trust. Most of the work, including representing the Trust at the public and voluntary group meetings, many of which took place out of normal office hours, fell on the shoulders of two people, Steven and the comparatively junior Clive. Steven as a Director was a full member of the Programme Board, while Clive also attended and contributed to meetings.

The rationale for these two people undertaking most of the work was that presentations would be of a uniform standard and that these two could compare the issues raised by different groups. However it also meant that few of the Programme Board were exposed directly to the strength of feeling of the public or had the opportunity to engage in debate. In particular, very few clinicians or Directors of the Trust were involved in meetings with the public at all, despite the early recognition of the importance of clinician involvement (North Bristol NHS Trust, 2001g) and the view that *"consultants carry weight"* (Helen).

The progress of the involvement work and summaries of the issues being raised in the meetings and other parts of the strategy were discussed at the monthly meeting of the Programme Board, often as the first agenda item. These discussions were often quite detailed, describing the meetings that had been held and the issues raised (Observation notes, Programme Board August 8, 2001). Those most active in the discussions

of the progress of the involvement work were the Planning team, the Chief Executive and the Communications team. Little part was taken either by the clinicians or the Finance Director. There was rarely any further discussion of the issues raised by the involvement during subsequent items on the agenda, in which the leading players were the clinicians, Finance Director and Chief Executive (Observation notes, Programme Board, August-October).

Discussion of how the views of participants might impact the plans was quite limited until quite late on in the process. At this point, in the early October meeting, the nature of the discussions shifted from collecting and reporting on local views, to what the Trust should do to influence the views of local people (Observation notes, October 8, 2001). The Communications team became more involved in the work with local groups and presented an analysis that concluded that there had been a failure to present the ideas of the Trust strongly enough. They suggested a number of ideas for shifting public opinion, including stimulating TV news coverage and producing supplements to local newspapers (Observation Notes, October 8, 2001).

What appeared to be missing from this analysis was any consideration that actually the ideas of the Trust might be flawed, despite a consistent message that most people saw development of a single site as offering poorer care for the many, reduced employment for local people and likely to worsen the traffic situation in North Bristol with consequences for access to all local services. These issues were completely missing from an analysis of demographic effects in a report to the Programme Board (North Bristol Trust, 2001l). This report considered only the impact on services provided inside the hospital, rather than conducting an appraisal of broader effects on the local community.

6.3 The purpose of the involvement programme

Among Programme Board members there were different views of the involvement process. Considerable support was expressed and several Board members voiced their admiration for the work done, but for some it was a question of personal belief in the process that would give a voice to *"many stakeholders who have different perspectives"* (Steven). Others saw it as a way to get 'accurate' information across to the public.

The purpose of the programme was not clearly defined by the Stakeholder Involvement Strategy, however it did note that it would be required under the NHS Plan (2000) and the NHS and Social Care Act (2001).
Interviews with Programme Board members suggest that there were a range of views as to what the Trust expected from their work and there was not a clear agreed purpose for the involvement of local people in the process of developing a Strategic Outline Case.

Some members of the Programme Board were strongly committed to the role of the public in decision-making. For one clinician, it was part of a wider change in society:

> *"This is what I do with patients, here is the diagnosis, we can do this course of treatment or this one or none, you decide. Whereas ten years ago I would have said...this is the diagnosis, this is the treatment, I will start it tomorrow. And they would have said 'yes doctor' and off we would go. It doesn't work like that anymore and I think for these planning things it can't work like that either. The whole atmosphere has changed."* (Richard)

For another Director of the Trust, the paternalism that had existed in the relations between clinicians and patients was also evident in the organisation. Shifting towards more of a partnership with the public was a way to improve services.

> *"For a long time, across the NHS, it has been a sort of mono perspective that it is sort of "what's good for you!" in a sense and actually, when you get out there, to*

> *talk to different groups, they have quite realistic expectations, but they have some very important perspectives...in terms of the way in which we can change our services."* (Steven)

A similar perspective came from another Director who emphasised the need for openness:

> *"I think we are scared of that...we are terrified of telling them there is something wrong. We shouldn't be shy of telling the truth. If there is a danger because of the way that we set up the healthcare service, or a risk, we should say there is a risk. "*(Jeremy)

There was not, however universal agreement. The Trust Chief Executive, who joined the Trust in the middle of the process felt that the Trust had stumbled into it without sufficient planning and saw it as simply fulfilling a requirement of the Strategic Outline Case process.

> *"...it was a consultative process which was required statutorily as part of a SOC submission...it was in that box and therefore a tick...rather than a deeper, broader analysis of well where are we going, what will the public really want to know."* (Terry)

It was clear from the interviews of managers and clinicians that in developing their involvement strategy, they had not been primarily responding to the statutory duty to involve and consult (Department of Health, 2001) or the needs of the SOC process. Most of the managers interviewed failed to mention the duty unprompted, even then stressing, "The reason for doing it is because people genuinely see the validity of this type of work and are then using the government guidelines to help" (Clive). One manager told me that the driver for the involvement was "a real belief that people have something to say and it just happened to coincide with the fact that government policy was moving in that direction" (Steven). Personal commitments like this were common to most Programme Board members interviewed, however they did not translate into professional actions and it is questionable whether they were matched by an organisational commitment. It appeared that despite the personal

commitments, the main reason that the programme of public involvement had been accepted by the Trust was that it was required by the process.

It appeared that in organisational priorities, the role of the public in decisions taken about the future of services would, in reality, be minimal (Observation notes, Programme Board May 28, 2001, October,8, 2001). Whilst they were signed up in principle, there was little evidence that their collective view could be changed significantly as a result of the programme of meetings, despite the strong messages that came back. And while there was discussion of public involvement at Programme Board meetings, it was limited to specific "public involvement items" and was rarely mentioned in the context of the plans themselves (Observation Notes, Programme Board May 28, 2001, August 8, 2001).

Later meetings of the Programme Board concentrated on strategies to change public views, to "get the public on our side" (Helen) or to present "our argument in a stronger way" (Observation Notes, Programme Board August 28, 2001). A phrase that I heard again and again in interviews of Programme Board members involved was "getting our message across". For most of the Board, this became the primary motivation for the whole involvement process "...the whole point of it" (Jill) as one person put it.

The scope for change was limited from the Trust's point of view. There were parts of the proposal for a single hospital that the Trust might possibly alter, even including the site, and omissions from their planning such as transport links, but the central issue for the Trust was not for negotiation. One Director told me that

> *"The site that we go to at the end of the day will probably be the one that's best for solving the access problems. If that's true then that is good for the public. If you think about it, it doesn't matter, it won't compromise my professional view so why should I worry?"* (Graham, emphasis added)

This serves to give credence to the public view that the Trust was going through the motions of involvement. The involvement was seen by local citizens as, *"an exercise"* and that the Trust *"....has to be seen to be consulting."* (Sally). Another person felt that the Trust had been forced into the public involvement programme by local media interest in the story:

> *"...because suddenly there was a lot of media confrontation and although I think the media – like it does often had grasped the wrong end of the stick, the fact that suddenly there was this barrage of, like criticism that sort of surfaced, meant that the Trust had to like really think of a way of neutralising that negative effect of the impression that was being given by the media."* (Owen)

From others there were stronger views about the process. One respondent, a regular contributor directly and through his MP commented:

> *"...to call it public consultation is a bit of a joke I think...I mean it was an opportunity for people to speak, but they were not prepared to answer sensible questions and they certainly weren't interested in getting people along to talk about these things. They only wanted to put their man up to state a few views and that was it."* (Walter)

6.4 The process of involvement

The Trust put enormous effort into the programme of involvement, but I wanted to examine whether their work met the needs or expectations of participants and whether Trust managers and clinicians were happy with the process.

The published view from the management of the Trust was that they had

> *"...successfully engaged the local community...by plugging into the existing networks of community associations, residents groups, area forums, urban regeneration projects and parish and town councils that were already coordinated by the local council"* (Maidment, 2001: p17)

This statement equates contact with appropriate community members with success in involving the public. In fact, simple contact may not be sufficient for the Trust to fulfil its statutory duty to "involve and consult"

(Department of Health, 2001). For example, Marsh et al (2001) suggest that a more complete assessment of the success of the programme needs to take into account a greater range of issues, including defining the role of the participants and the impact of participation.

Although the Trust recorded information about which groups were involved (Maidment, 2001), no individual demographic information was recorded at the public meetings so there is little information about whether all sections of the community were involved. Questionnaires collected from focus group participants did include some basic demographic information. They reveal a roughly even split between men and women, but an older group than the population in general, averaging about 55 years and with no representation from under 35s (Shepherd, 2001).

Full engagement would also mean that groups with specific needs were enabled to participate. Several people with mobility problems attended meetings and one commented:

> *"I think in some ways, the actual group I went to could have been better organised. Like taking into account access needs for people. There were a few people who had hearing impairments and there was no loop. You know usually with proper consultation with people, you make it as accessible as possible and that actually made it quite difficult for some of the people in the group to participate, because there was no induction loop. I myself am a wheelchair user and it wasn't the most friendly of places. It was going upstairs and the doors were heavy and things like that -- which in some ways for consultation, you need to make people feel as comfortable and make it as accessible as possible."* (Sally)

People may have been excluded if they were unaware of meetings and there was some criticism of the advance publicity of the meetings. The Trust, on the other hand, felt that they had made efforts to ensure that people were aware:

> *"All the meetings that we arranged were published in the local press and were on our website...we used the Evening Post and the free papers, parish magazines etc"* (Clive)

But one participant found out only the day before the meeting that it was happening, meaning that there was *"...only a half full village hall"* (Walter). Another was unable to go to a meeting as *"...there was actually a muck up on one meeting that I wanted to attend, where I was given the wrong date"* (Owen).

According to the trust, some efforts were made to ensure that the opportunity to participate was available to all by offering minority languages and a range of formats on request to those who received the leaflet and by making additional efforts to involve voluntary groups of or for older and disabled people. Community groups participating included several from areas of social exclusion within the Trust area. (Maidment, 2001)

The process chosen for the distribution of the leaflet was quickly recognised as flawed with several parts of the area not fully covered or missed entirely as they do not regularly receive free newspapers. Steps were taken to rectify this using the post and other methods for distributing additional leaflets. More successful were contacts with known voluntary and community groups, many of whom sponsored meetings or invited the Trust to send representatives to make presentations to meetings.

The meetings themselves took a number of different forms. In some, the Trust was allocated time as part of a wider agenda, limiting the opportunity for discussion. In other meetings, the format was also a presentation of proposals, followed by a discussion, however as the sole purpose for the meeting was to discuss the Trust's proposals, there was more time for presentation and discussion. Programme Board members felt that these worked well and described a meeting in Frenchay:

> *"We were right in the lions den in a sense, the people who were most vociferous about keeping Frenchay open. We spent an hour, S and I putting over the financial and the professional and clinical stuff. And then we had a really good debate with...the hall was full, there would probably be 150 people there. We had a really good debate and my feeling after that was that the vast majority of people there did have an understanding of the problems, they were sympathetic and they weren't just saying no you can't close Frenchay, they had got round to the point of saying OK, we know there has got to be a change, but we want to make sure we have got good access to whatever you are planning. It all came down to access, not to "You have got to keep Frenchay"...So it sort of shifted to that ground. I thought that was very positive."* (Richard)

There was, however a different perception was offered by a member of the public who attended the meeting in Frenchay:

> *"...there were no leaflets delivered in the Frenchay area and it was only the parish council calling a meeting and inviting speakers which caused anyone from Frenchay to be involved at all".* (Walter)

Participants in the focus groups were self-selected from those people who had already been involved in some other way, either through attending meetings, making telephone contact or responding to the leaflet in writing. The focus groups were based on a topic guide rather than presentation and were moderated by facilitators not employed by the Trust, but employed within the local health service (led by the author). Participants discussed the issues in some depth and were asked to complete a decision sheet concerning their view of how well the local health service responded to patient need, the desirability of the development of services in the community and making a choice of which of the options outlined by the Trust they would prefer.

Evaluation sheets from the focus groups (Shepherd, 2001) show that for most people (88 per cent) this was the first time they had been involved in this kind of process. However, many were active in the community in other ways either as members of community or church groups, or in the voluntary sector. Almost all thought it likely that they would be involved again, given the opportunity. More than 90 per cent felt that they had had sufficient opportunity to make their views known and 70 per cent were left

with no further questions about the subject, even so, most (68 per cent) thought that their views would not affect the final decisions. This issue deserves further investigation and the interviews provided the opportunity to develop more of an understanding.

In both the focus groups and interviews there were suspicions that the process was not really part of the decision-making process, but that decisions had already been. One key influence on this was the memory of previous planning processes that had led to the closure of hospitals.

A Programme Board member agreed:

> *"...for some people, they thought it was just a rubber stamp and that we had made the decision. No matter how much we said that we hadn't, they just retained that view. I suspect that reflects some of the things that had happened in the past. There have been other public consultations where people have already made the decision, like the closure of Ham Green Hospital. I'm not surprised the public are cynical about it. The public consultation around that was negligible."* (Richard)

The history of (not) involving people in making health decisions in Bristol was raised several times by focus group participants and in interviews. Criticism of the processes for decisions about the new Bristol Children's Hospital (too small and in the wrong place) were common, as were those about South Bristol Hospital (still waiting after 30 years), the controversial closure of the hospital at Ham Green (promises of a replacement were not realised) and an abortive proposal to close the nearby Cossham Hospital (eventually rejected by the Secretary of State).

There seemed to be a number of components to the lack of confidence. People were unsure about the decision-making process. Some felt that the decision had already been made and that the involvement programme was little more than window dressing or *"...one of the cheapest PR exercises out"* (Focus Group, Yate). For others the question was of the motivation for the plans and the transparency of decision-making:

"For me it would be really important to understand what is the driver behind the new hospital. What is it that is driving this agenda forward and why? And then you can begin to understand and to reason it out. Then maybe you can have some kind of informed debate." (Dipak)

The issue of trust in the decision makers at North Bristol was also recurring theme for focus group participants and those citizens interviewed. One person commented that she would be more confident of the outcome if she felt there were more independence in focus group facilitation,

> *"I mean what does worry me is whether it is consultation that's being done by the health authority, for the health authority, whereas sometime consultation is better if it is done by a third party."* (Sally)

This kind of comment was made many times in the focus groups themselves and was a view that appeared to be held by many participants, who assumed close links between the different organisations in the local NHS.

The other process issue identified in the Trust's strategy was the importance of feeding back the results of the meetings to those who had participated. Their approach to feeding back was, in addition to any publicity generated, to undertake follow-up mailings to those who had participated in the meetings or had contributed their thoughts by mail or telephone. There were two mailings during the involvement programme, both of which essentially fed back what had been said at meetings and which issues were most of concern to participants, without indicating what effect the discussions had had on the thinking of the Trust.

For one of those who was involved mostly through correspondence, but also who attended a meeting in his local area, the process of feedback had been very frustrating. His view was that the Trust had failed to answer some very serious questions:

> *"Nobody has answered the two points I made just now about the reduction in... beds or the point that it would delay improvement in health care in the area by many, many years. No one has answered these points. The MP made them as well. He didn't get any reply. I think they are just hoping that these sort of difficult issues will go away...I have no idea what is going on in their minds."* (Walter)

Cook (2002) discusses the components of proper feedback in the context of consultation or involvement. Her view is that it is a three-part phenomenon, consisting of the results of the consultative work, the action taken as a result and where the action was not taken, the reasons why. The Trust fed back the results, but failed either to detail action or reasons for non-action. From the focus groups, there is evidence that people felt that they had been offered the chance to make their views known. Interviews with people who had attended other meetings confirm this and even those critical of the involvement process confirm that they had opportunities to contribute. However data from the evaluation questionnaire shows that less than one third (32 per cent) of participants thought that their views, individually or collectively would make a difference to the ultimate decisions taken following their involvement and one focus group participant commented in an interview:

> *"There was a great deal of feeling that no matter what we said, the decision would not be affected. There was doubt about it then lets put it that way...It was being said that it was all cut and dried at one time and some people were suspicious that it was just a con game going on."* (Isabel)

Other comments about the response of the Trust also criticised it as limited to summarising contributions made, rather than demonstrating progress in developing proposals. A focus group participant drew a distinction between the immediate "listening" of the representatives of the Trust and the organisational response:

> *"I felt we were listened to then, yes...I mean you listened and the people who were present at the meeting certainly listened. But I mean how far they really responded, I mean what we've seen are summaries of the work that was done*

> *and the meetings and so on. So I mean, how the Trust have responded to all this representation, I am not really sure."* (Walter)

There was agreement from some Programme Board members that the Trust was unprepared for the contributions people made. The new Chief Executive told me *"the Trust didn't really know what to do with it..."* (Terry), while another member of the Programme Board thought they had not *"assessed what...was important by way of engaging the public"* (Jeremy) however in its report of the stakeholder involvement, the Trust also commented that

> *"Many people felt that the consultation exercise would only be worthwhile if staff, patient and community views were listened to* ***and acted upon*** *(emphasis added)* (Maidment, 2001: p. 7) and
>
> *"The Trust needs to demonstrate in a practical way that it is listening and will respond to what people are saying. It is much easier to engage with people and so adapt plans or build in new thinking, than to alter or add to final proposals as a result of widespread public and staff criticism"* (Maidment, 2001: p. 11)

What appeared to be happening was that in print, the Trust was saying the 'right things' about being inclusive and adopting open and transparent processes, but the reality was that they were neither open nor inclusive and the Programme Board knew this was the case.

There was real concern among citizens about whether their views would count for anything. This was a concern for the Citizens Panels and focus group participants. Some of those interviewed felt the same.

> *"My big concern is that it will get pushed through whether the general public agree with it or not. I've seen this too many times before."* (Owen)

Perhaps the most revealing remarks came from those members of the Programme Board commenting on their overall impression of the process. The new Chief Executive thought that though the content and the organisation of the meetings was very good and the public provided a valuable and constructive contribution, what was missing was a cohesive,

strategic vision so that he did not *"think that we engaged the public with any purposeful motive"* (Terry) another thought *"...we really didn't want them to create any problems for us, we just wanted to get a tick in the box..."* (Steven) Some members of the public held similar views, a focus group participant, for example said, *"I could be cynical and say that it has to be seen to be consulting."* (Sally)

Others, including many of those who took part in focus groups participated despite believing that their views would have no impact and that decisions had already been made. There is considerable justification for this opinion. A few Trust interviewees were at pains to state that there had been no decision, however they also stressed what would *not* be acceptable to the management and clinicians in the Trust. That was the retention of both hospitals in their current roles. In effect, this meant that although there were decisions still to be taken, others were not up for debate so that the real scope of the debate was much narrower than the Trust admitted.

There was a feeling among members of the public that the process had already gone too far, that decisions had already been made and the Trust was unwilling to change its views in response to public feelings:

> *MS "Did you feel that the Trust were willing to change their ideas in response to what people said?"*
> *Walter: "Well I wasn't sure about that. I mean I don't think that emerged. And I think some of the documents that emerged afterwards rather suggested, you know that...um...that might not be the case."* (Walter)

The third area that was identified by the Trust's Strategy was to ensure that accurate information was available.

An important aspect of the process for most was *"giving people information, so that they know to some extent what is going on"* or *"getting accurate information across"* as *"there were quite a lot of myths going*

around...".(Richard). But the 'myths' persisted and most of those citizens who were interviewed had not understood the background to the proposals or the process of decision-making.

The lack of clarity about what one person called "the drivers for change" (Dipak) at least in the published material meant that the programme failed in what some people assumed it was meant to do, to get the Trust's message across. From the perspective of the consultants, the drivers were quite clear. The Joint Chairmen of the Consultant Medical Advisory Committee wrote to the Trust Chair...

> *"The most important driver for change is the considerable improvement in quality of care..." (Letter from Joint Chairmen, Consultant Medical Advisory Committee, reproduced in Maidment, 2001)*

The response from the local press was to present the changes as necessary due to the state of the buildings at Southmead and Frenchay. Both the Evening Post's story (Onions, 2001a;b) and the Western Daily Press (Ribbeck, 2001) put across the reasons for proposing development much as the Trust presented them, as a means to improve care for patients. The headlines *"£240m Health Tonic"* (Evening Post, 25/7/2001) and *"£210m vision for Bristol hospitals"* (Western Daily Press, 26/7/01) are upbeat and the stories that accompany them largely positive, stressing the Trust preference for a new site (Onions, 2001b; Ribbeck, 2001).

Despite this apparently positive coverage, the Programme Board minutes for August report that *"public opinion was still being significantly influenced by the media"* (North Bristol NHS Trust, 2001c). Although no further explanation is given, it indicates some dissatisfaction that members of the Programme Board felt about the presentation of plans. Some Programme Board members felt that the press had put too much stress on the green field option. For example, it was "...where the hospital might be that got everybody on fire" (Observation Notes, Programme Board August 28,

2001) and *"...they were standing up on the Harry Stoke site with their hair blowing in the wind, speculating to camera about the preferred site"* (Helen).

One Trust Director acknowledged that part of this was the result of the press launch at which the Trust Board had *"said that our preferred option would be to build on a green field site"* (Jeremy), so it could well be interpreted as "friendly coverage" from the local media supportive of new development.

The role of the media in informing the debate was discussed by a number of people. For some, the role had been underdeveloped. One Director thought that by not working more closely with the local press, an opportunity to get the message across had been missed:

> *"We should have engaged with those people. I would have loved to have seen a series of television programmes...done in collaboration with local television. To really engage through television and radio with the issues..."* (Graham)

There were suggestions in the Programme Board that there should be a paid "advertorial" giving the background and reasons for the proposals or a "serious" television report (Observation Notes Programme Board, July 31, 2001). But others were less optimistic, recognising that *"its hard to put a complex story across"* (Helen) and that the media likes controversy:

> *"...they tend to like the more sensationalist side...its much more interesting to talk about where A&E might go than where you would go to get your dressings changed...the press tend to dictate their own agenda"* (Jill).

For another member of the Programme Board, there was a similar frustration about the presentation of the story:

> *"The press had taken our options and taken the most newsworthy...it wouldn't have been newsworthy to say that Southmead and Frenchay are to stay the same...If you want to get a message across you have to use the media...the risk is that they will transmit the message they want".* (Jeremy)

There was also confusion over the extent of change being envisaged. Not only did the local Health Authority announce a wider review as the consultation proceeded, but local consultants also began a campaign for a single hospital for Bristol (Key, 2001), so that the press was covering several overlapping stories in quick succession. The consultants' campaign could also account for the press concentration on a site for a new hospital. The confusion over several similar consultation processes at about the same time undoubtedly contributed, but none of the citizens questioned, all of whom had been involved in Trust sponsored meetings, talked about the proposals for developments in the community or accepted that care would be improved by concentration on one site. In their contribution, the Trust's staff, through the Joint Unions Committee commented:

> *"It is not immediately apparent how the proposals facilitate delivery of...high quality tertiary services.* ***We recommend making these links are explicit in presentations"*** *(original emphasis)* (Joint Unions Committee letter to North Bristol NHS Trust, reproduced in Maidment, 2001)

There were two views about how this might best be done. For some, it was the media, for all of their faults, provided the most likely vehicle:

> *"I think there is a big bulk of the general public that believe...I mean if they are told something forcefully on TV...they believe it. Bearing that in mind, we have got to get those people singing our tune if we can. Because it is powerful. For a big chunk of the population, if they see something on Panorama or Horizon or these sorts of programmes, they believe it."* (Richard)

Others recognised that the best promoters of their views were professionals, the "headline makers" as one Programme Board member called them (Observation Notes Programme Board, July 31, 2001):

> *"People believe what a doctor says, we learnt that very early on, they've got the authority. If a manager says it, it's perceived as cost-cutting or reducing the number of beds"* (Helen)

Despite this view, and the strong support for their message from the consultants at North Bristol, the Trust largely failed to get consultants involved in meetings with the public. This may have influenced the local public's view that the background to the proposals was financial or political, rather than about improving health care.

> *"Decisions like this need to be based on clinical views... The hospital is a political icon that I think the general population think are great, but it needs to be clinical need, not political need"* (Samuel)

What the evidence shows is that the Trust had not prepared itself to involve the public in its decisions. It had a history of poor decisions and poor communication to overcome, but it devoted no effort to improving these. Instead, the development of the plans in this instance replicated that bad practice and communications. The Trust regarded public involvement as a bolt-on to their existing process, rather than a fundamentally different way of working. They underestimated what public involvement would mean for the organisation as a whole. There were no processes established to develop plans in the light of changed views as a result of the involvement. There were issues raised by the public that had not been considered by the Trust. These issues included the wider consequences of developing a single hospital site, including the employment consequences, particularly in relation to lower paid workers, many of whom were locally recruited, and the environmental consequences, especially the increase in traffic in an already congested part of Bristol.

The information provision was also flawed. The distribution of the original leaflets was imperfect, but more importantly, despite friendly press coverage the Trust's views were never accepted locally. This may be partly due to the lack of trust, but is perhaps more to do with their inability to address people's real concerns. The plans were for high tech, very

specialist services, whereas local aspirations were much more down to earth.

6.5 The impact of involvement

As noted earlier, the Trust assessment was that the programme had been a success in that it had made contact with a large number of people from the local area. The broader view, encompassing issues of the management of the programme, representation and inclusion, opportunities for impact on decisions, transparency and responsiveness were examined through the interviews of participants and Programme Board members.

Some of these issues have already been discussed, but the outcomes of the programme of involvement and issues relating to the purpose of the programme deserve a fuller analysis.

This was the first time the North Bristol Trust had attempted to engage local people in a discussion about the development of their facilities although they had held meetings previously about the establishment of the Trust. They were fortunate that one member of staff had extensive previous experience; while the views of several members of the Programme Board meant that they expressed strong support for the principle of citizen involvement in decision-making.

There can be little doubt that as the public became more involved in the process in North Bristol; the Programme Board became more interested in what they had to say. Notes from early meetings suggest that the Trust originally envisaged the local Health Authority taking on most of the citizen involvement work (North Bristol NHS Trust, 2001c;d;e;h). Early on, also, the Programme Board spent little time on the issue in comparison to technical aspects of the planning process. Following the development and

implementation of the stakeholder involvement strategy, they seem to have recognised that this was an important part of their task and began to spend much more time discussing the issue (North Bristol NHS Trust 2001b;g;i;j;k). The concentration in the Board was, however, always on trying to put across a corporate point of view, rather than on engaging in a dialogue.

The framework developed by Marsh and colleagues (2001) is valuable for a full assessment of the success of the programme. At the core of the Trust's view was the idea that providing information to the public was their most important role. A number of people said this in different ways. For some it was about setting the record straight, where the Steve Webb survey and the press coverage had given alternative versions of the relevant information. While many concentrated on the importance of getting the Trust view or version of the facts across, one member of the Programme Board identified a three-step process of information, discussion and consent:

> *"Informing the public, making sure they have got all the facts and that they are in a position to make a good judgement"* (Clive)

Clive's position is idealistic and a rationalist approach which, like Habermasian ideas of the public sphere (Edwards, 2004), assumes openness and pluralism in the decision-making process, including a role for the public, and ignores contextual issues such as existing power relations. Compare this to a similar quote from Richard, who also recognises the importance of public support, but minimises their part in the process of decision-making.

> *"(what we were doing was) getting to the point of getting the public's support for changes. Because then it is much more powerful when you go to the politicians with your case for change" (Richard)*

Clive's comments appear to separate the public discourse from the policy process. His position assumes that the Trust has "...all the facts" and can judge which are the important issues. From the involvement process, and from their own reports (North Bristol Trust, 2001l), there were consistent messages that this was not the case and that some of the most important arguments were based on information gathered by participants from other sources or different perspectives on the underlying problems of the local NHS.

Providing information to the public is widely recognised as an important part of involvement which should be an enabling influence in the construction of public involvement, however the theoretical perspectives on involvement such as that developed by Arnstein in her ladder of participation, suggest information provision is a form of partial participation however it falls some way short of full participation.

Accepting that citizens can bring relevant information and perspectives to all areas of a debate is a step that the Trust had not taken towards full participation.

A useful distinction in terms of involvement is between direct and indirect approaches (Richardson & Bray, 1987). As the term suggests, direct involvement refers to processes where people participate directly in decision making. In indirect approaches, the input of participants is mediated or interpreted by others before being considered by decision makers. This imposes a process through which the structural power of the organisation can be defended. All of the methods for public involvement used by the Trust were indirect, with public views recorded and synthesised for the Programme Board. In Arnstein's terms, this meant that the strategy could only ever reach "partial participation", but the advantages of more direct approaches were recognised by one of the Programme Board:

"...I think we need to think about what will make an impact on us in the meeting, in our business, in our decision making, in our agendas and not just from a distance when we get reports back from the public involvement...So I think it is getting the voice actually at the Programme Board that we need...the face to face challenge of questioning is really valuable" (Charles)

Charles viewed his relationship to the Programme Board as less than a partnership and his recommendation for direct involvement was not taken up by the Trust. Only in a few meetings were Directors or clinicians actually exposed to the views of the public. What has to be asked is whether the Trust as an organisation demonstrated any commitment to meeting and engaging in debate with local people. As one Programme Board member said, face-to-face responses can be much more powerful. He recounted his experience of one difficult meeting:

> *"I know that one of the principle proponents of a centralised hospital came along with me to probably the grumpiest meeting of the lot organised by the Socialist Alliance and didn't dare espouse his particular cause when he saw what was going on in the process and what the reaction was and probably, he started to understand that what he was putting forward was an ideal, but it wasn't sort of something that you could just easily deliver." (Richard)*

If the effects of exposure to public discussion are as effective as that, the Trust missed the opportunity to "get their point across" by limiting the participation of Board members as they did. According to Helen who commented that *"consultants carry weight"*, they realised the power of clinicians early on, but never used them, even though their ultimate purpose in involving local people was to change their minds. Had the Trust not argued that their purpose was changing the public view, they might argue that in not involving consultants, they were enabling fairer discussions, minimising the impact of the Lukesian power of the consultants. As their purpose was described however, it represents a significant tactical error.

Among participants, the understanding of the purpose of the stakeholder involvement programme tended to be that it was "window dressing" at best and manipulation at worst. Nonetheless, many people wanted to register their feelings, their expectations however were limited. Among citizens who were interviewed, the majority felt that although they did get information from the Trust, they did not get responses to questions and they could not see how their comments had been used in making decisions or where changes had been made. Few of those who were interviewed or taken part in focus groups thought that anything they said would change the decisions of the Trust. This suggests that participants felt the decision-making was not fully transparent; in particular it was unclear how the citizen involvement fit into the overall decision-making process. However as members of the Programme Board point out, the Trust was also not clear on this point. They had not considered in any way what their responsibilities were in undertaking the programme of involvement.

There was a developed Trust preference for one option in the proposals they were putting forward, despite the assertion in the published literature and elsewhere that no decision had been taken. The preference for a single hospital site was one rejected by a great majority of those involved in meetings, in focus groups, in the Citizen's Panels and in the Steve Webb survey, however the Trust did not attempt to engage in this debate by detailing the reasons for their preference or acknowledging that there was an argument against their position. Their implicit view as an organisation was that there was no local accountability for their decisions.

For the Trust, the involvement work provided a good deal of information about how the local public were thinking and what issues were likely to cause the most concern, enabling them to prepare responses.

"To me, what we have done is drawn fire. We found out what are the key issues that concern the public about this development." (Steven)

What Steven does not suggest is that the Trust would do anything to address the key issues, this "drawing fire" function of public involvement was very useful for the Programme Board in assessing what additional work it needed to do. However there was no suggestion that whatever local people said, the core proposal that there should be one hospital in North Bristol could be changed, even though much of the material distributed to the public suggested that there remained an option to retain both hospitals in their current form and a clear and persistent majority of local people supported that option.

In an important study of public and user involvement, Harrison and Mort conclude that for NHS organisations, involvement functions as a means of bolstering the positions held by professionals and managers, what they call a technology of legitimation (Harrison & Mort, 1998). Where results are helpful to their position, they are highlighted, where they are not helpful, they are marginalized. In the North Bristol case, where the views of local people contradicted those of the Trust they were excluded from the debate. Here, the Trust interpreted involving the public as informing the public. Local views were listened to but not heard. Information provision begins here to look very like manipulation, especially when considered in the light of comments about "drawing fire" or technologies of legitimation. On the other hand, some issues were raised by members of the public, particularly concerning transport and access that had not been considered by the Trust. On these issues, local citizens made a significant contribution and called the Trust strategy into question. This analysis demonstrates the limitations of Arnstein's approach. The ladder of participation on its own looks inadequate to explain the pattern of involvement in North Bristol.

Stretching the model into the two dimensions identified by Skelcher (1993), we can note a hierarchy of decisions to be taken, some of which can be seen as central to the Trust's plans, others of which were more peripheral. The concept of rationalising services was central, location peripheral, at least for the medical director. The model could also be adapted to examine the citizen's perspective. For the citizens there were also issues that were regarded as central to their use of the services, such as access to local facilities others that were peripheral, such as the location of specialist services.

If some decisions, essentially those that are peripheral to the organisation's long term functioning or the professional interests are more open than strategic issues and those impacting strong professional beliefs. These in turn are more open than issues that challenge structural interests. So the Trust will incorporate local views of the process of service delivery or even the location of hospitals, but will resist involvement in decisions about the 'model of care', the number or funding of main hospitals or the prioritisation of acute illness over chronic conditions. But the citizen's view has its own 'red lines' drawn around local access to services. On these issues, there may be more resistance (as there was in Kidderminster before the 2002 election) and a serious challenge to the professional view.

The view expressed by Graham, that only issues that "compromise my professional view" are not negotiable establishes the area for discussion. Sites are negotiable, but the concept of the single high tech site was not. The problem for the Trust was that this very issue, the number of hospital sites, emerged as the issue to local people.

Although several senior Trust staff attended one or two public or other meetings, the vast majority of the meetings were staffed by one of two people. The contribution of these two was acknowledged by several of the

Programme Board, while people who attended meetings also commented favourably about their presentations and responses to questions.

From the public perspective, the involvement programme undertaken by the Trust, even if it did not result in the closure of a hospital, may have confirmed their fears that it amounted to window dressing or a cheap PR campaign. There was precious little chance that their views would have an impact where they thought it was most important.

The case study should be viewed in the context of both the national policy agenda and developments at a local level. National policy, while promoting public involvement in decision-making focuses more strongly on improving efficiency through performance measurement. At a local level, the Trust's clinicians developed a vision of health care based around leading edge healthcare emphasising specialist care. This contrasted sharply with the view from primary care providers who sought high volume general services as a priority. The result was an uneasy model in which devolving general services and centralising specialist services attempted to meet both visions. Within the Trust, the hospital clinicians' vision was dominant and despite the need to meet national priorities for volume services, the management of the Trust supported them.

The ability of the consultants to control the agenda of the programme board appears to be a demonstration of the strength of the Lukesian third dimension of power. Not only were they able to dominate the development of the model of care, even against the preferences of their colleagues in primary care, but the Directors of the Trust did not question their conclusion that this was the appropriate direction for health care in Bristol until the new Chief Executive began taking about a "whole systems model of care" (Observation Notes Programme Board, October 2; North Bristol NHS Trust, 2001k).

What is also evident is the frustration that citizens felt at their inability to get their agenda addressed by the Trust. However unlike Saunders' South Londoners (Saunders, 1980), the Bristolians were still willing to participate and not only to become involved now, but in the future, despite feeling that their input would make no difference (Shepherd, 2001).

The indirect processes employed by the Trust meant that the views of local people could not have an impact on the decision-making process except through the mediation of NHS managers and professionals. Even then, while reports from the Trust and from the focus groups identified flaws in the planning process, there was no discussion of change to the plans. Only in Richard's discussion of his encounter with the Socialist Alliance was there evidence of direct contact with clinicians – and it appears that the flaws in the vision may have become apparent as *"...he started to understand that what he was putting forward was an ideal, but it wasn't sort of something that you could just easily deliver."* (Richard). This was an example of how the *exercise* of power at a micro level can weaken the structural power of the Lukesian model. In this case, through confrontation with an interest group that collectively can overcome structural constraints, but in the formality and structure of most public meetings, there will be limited opportunities for this kind of discourse.

The Trust initially viewed those who contributed their views as "service users". The strategy approved in May by the Programme Board was for "User involvement" (North Bristol NHS Trust, 2001i) and although the language had shifted to "stakeholder involvement" by the publication of the final report (Maidment, 2001), the Trust still had a limited view on who would be qualified as having a valid viewpoint to contribute. They had not considered that local people were also citizens, who additionally have an interest in being involved in decisions over which services are offered.

6.6 Summary

There was no sense in which the Programme Board viewed local involvement as really part of their decision-making. Individual members, while they may have professed a belief in public involvement did not perceive their accountability to the public, but to the Trust and the NHS. The involvement was not initially understood as a means to establish legitimacy for their decisions but to fulfil the needs of the process for the Strategic Outline Case. It was a process that had to be undertaken, but not envisaged as one that should delay or impact the submission. This comfortable view was shattered by the opposition which was greater than anticipated and rather more reasoned. It was not only defending the status quo, but arguing for an alternative and broader model of care that took issues of environment and employment into account. There was a shift in the perception as the process advanced. The Programme Board began to see the involvement process as a way to explain their view of the future of hospital care and did not understand that opposition might be the result not of their vision being misunderstood, but that it was fundamentally flawed.

Seen from the perspective of the ladder of participation, the North Bristol Trust never progressed beyond giving information to the public, there may have been a possibility for more involvement in decisions about a final site, had the project progressed that far, but these issues were defined by the Trust Medical Director as unimportant to the professional goals of a single hospital.

However, this was not really the view of the Programme Board as a whole who did not act on any of the responses and at the end of the process defined the purpose of the involvement as *"getting our point across"* (Jill). Involvement, while it did prove unsettling for the Trust, never really influenced decisions taken by the Programme Board.

Chapter 7: "Getting rid of the suit": involvement in community decisions

7.0 Introduction: A brief history of the Knowle West Health Park

Knowle West is a large local authority housing estate in the South of the City of Bristol, identified as an area with a high level of deprivation by government statistics (DETR, 2001). According to locally produced statistics, Knowle West residents suffer from excessive premature mortality from heart disease and cancer, while levels of smoking are thought to be close to twice the national average (Pilkington, 2003). The epidemiology tells only part of the story, however.

Traditionally, Knowle West residents were employed by the tobacco industry in Bristol, first in the Bedminster area and later at Wills' Hartcliffe factory. The factory closed several years ago causing a significant increase in unemployment. The area has received funding from a number of regeneration initiatives in recent years and is now a Neighbourhood Renewal Fund area, one of three in the City of Bristol. There is also a Sure Start covering the Filwood electoral ward, which covers approximately the same areas as the Knowle West estate.

The Health Park project provided a long-running well defined example of a locally based scheme that was explicitly committed to local involvement and adopted a social model of health in common with that of the public health approach (Wharf Higgins, 1999). The case study critically examines the involvement of local residents in the whole of the development, including a focus on recent work within the Knowle West Health Action Group. The development of health priorities through this multi-agency group, which included local representation, provided an opportunity to observe the process for involving local residents in decision-making.

The research sets out to consider the local circumstances and culture within which the Health Park was developed and to move beyond a description of the methods or results to an understanding of what it is about the community, the agencies involved their interaction and the approach to involvement that has led to the outcomes as we see them (Pawson & Tilley, 1997).

The study uses multiple data sources (see Table 7.1). Informants were primarily local residents, staff, professionals, managers and strategists, but these data were supplemented by documentary analysis and observation notes from the meetings of the Health Action Group. Interviews and focus groups and the initial stages of the analysis were undertaken in cooperation with the University of Bristol, Department of Primary Care, who were responsible for the overall evaluation of the Health Park development.

We purposively sampled a cross section of professionals and local people involved in the Health Park. Interviews were supplemented by focus groups of local people who had different levels of involvement at the Health Park and for my research by observation at meetings of the Health Action Group between March and October 2002.

We drew from three key groups. The first was identified from those believed to have been involved in planning meetings or decisions on behalf of the organisations involved in the health park project, including members of the Health Park Policy Group, Health Park Steering Group or the Health Action Group. These were people employed by the Health Authority (and later the PCT) or by Bristol City Council or working in the voluntary sector. The second group were local people who were identified and accessed via local community groups or had been involved in one or other of the Health Park Groups. These were people active in the

community, either in the Health Park or elsewhere. The third group were local people who had not had any significant involvement in the health park, but were registered at the surgery on the health park site.

Table 7.1: Interviews, Focus groups and Observations: Knowle West Case Study

Name Used in text	Status/role in local community
Harold	Project architect
Damian	Community Work Manager
Sandra	Health Living Centre Manager
Tony	GP
Brian	City Council – Manager
Kev	Community Worker
Martha	Health Centre Manager
Barry	Social Services Director
Simon	Environment, Transport Services Director
Denise	Chief Executive, Primary Care Group/Trust
Karen	Assistant Director of Primary Care
Rita	Local Activist/Lay member of PCG
Colin	Planning Manager*
Donna	Community Development Manager*
Sarah	Community Worker (Voluntary Sector)*
Anne	Community Health Manager*
Fran	Public Health Manager*
Hilary	Housing Services Manager*
Dermot	Public Health Director*
Lesley	Regeneration Director*
Mike	Health Park Manager*
Terry	CHC Worker*
Maggie	Local Activist/Lay Member PCG*
Malcolm	Development Trust Chief Executive*
Virginia	Health Policy Manager*
Cath	Local Activist*
Kelly	Local Activist*

Those marked * were interviewed by MS

Focus Groups
Health centre patients (2 groups)
"The Park" – Community Education Centre
Young mums group

Observations
Neighbourhood Renewal Health Action Group (6 meetings)

The importance of understanding the history and character of Knowle West was emphasised by a number of informants. Local people expressed their mistrust of local decision-makers, often citing broken promises over the issue of the "South Bristol Hospital", an often planned, never (yet) developed facility. This long running saga was raised by all of those local people interviewed.

People who live on the estate have gained a reputation for activism. A group of local activists, mostly women, have raised their concerns often by circumventing the local decision makers, preferring more direct ways to raise their concerns. For example, for local people, issues of access to treatment for drug users and crime resulting from drug use have been shown as the highest profile issue (Bristol City Council, 2002) and one of the impressive examples of this is how Knowle West Against Drugs (KWADS) has established a national profile through coverage in the national press (News of the World, Real Britain series, 2000-2001) and contacts with high ranking politicians, including Tony Blair and the area's MP, Dawn Primarollo. Representatives of KWADS have been invited to Downing Street and received a return visit from the Prime Minister who came to the health park in the summer of 2002.

One of the Bristol City Council's senior managers gave her view of the nature of the community

> *"I don't think you can think of Knowle West and not see it as an area with very strong local community who have been very actively involved for quite some time. There are a number of very key individuals in Knowle West, who have played an absolutely major role in raising the profile of the area, demanding that more resources are brought in that the things that need to be tackled are tackled."* (Lesley)

One of the local people interviewed offered a similar view:

> *"We are a bit different in Knowle West; I think there are some exceptional people. They may not have the qualifications, but they have the brains, they are sharp. I think we have something special, I don't think other areas have the spirit that Knowle West has got."* (Cath)

The evolution of the health park began in the mid nineteen nineties, as part of a long term plan to replace Bristol's aging health centres, the local district health authority began talking about plans to replace the William Budd Health Centre in Knowle West, the oldest purpose built Health Centre in the UK. The planning was led by the Health Authority's Assistant Director of Primary Care (Karen). In a previous post, her enthusiasm for local involvement in planning decisions had developed, following involvement in the Health Authority's 'Person-to-Person' programme for involving voluntary groups in strategic health planning (Shepherd, 1995; Burton, 1994).

Through contacts in the City Council and local voluntary sector, she gathered together a group of professionals from several different backgrounds who shared a belief that this was an opportunity for a unique development that would work with local people in new and different ways. One of those involved described the group as

> *"Very good bunch of people who were really interested in what the voice was that was coming from the community...they were an influential bunch of professionals...(and)...a group of people I felt very at home with and we were able to think out of the box"* (Harold)

The Knowle West project became a partnership with the local authority, when they agreed to allow the Health Authority to use the site of a former secondary school for the health centre development. The school site had closed years earlier and had been plagued by vandalism ever since. In a final act, it was burned down.

Karen had already led discussions with staff and local residents in which she encouraged them to *"Shoot for the moon"* (Maggie) and to try to imagine a different kind of health facility that would respond to the needs of the local community. The notion of a "health park" emerged, inspired by developments in Liverpool and Peckham, with meeting places and facilities for exercising, gardening and education as well as a health centre. Harold described it as a *"...wacky idea"* which came from discussions with a number of community workers he met regularly when *"...involved in a lot of community projects of different sorts".*

While the term may have seemed simple enough, the detail of the concept was a bit more illusive, but one or two features could be identified that were agreed by those working for the statutory authorities and people living in the area. It would provide health services, yes, but more than that, it would support people to improve their health. The Director of Public Health was impressed:

> *"I think the reaction from the local community was such that they understood the concept, in large numbers. Yes, it is important to have facilities local facilities that we can use, because we are a community that feels itself to be cut off and isolated and out of the loop on the one and, but on the other hand, striking sophistication of their appreciation of the other things that a community needs to be healthy."* (Dermot)

In a preliminary evaluation of the health park project, Scott and Salisbury (2001) identified *"User involvement... (as)...central to the philosophy of the Health Park"*. Another informant, an experienced health service planner agreed:

> *"one of the principles and philosophy of the whole thing was that this was about developing a service that reflected not just what local people needed from a statutory agency perspective, but actually getting them involved from the very beginning and well integrated into the project from the very beginning. So that the whole thing was based around understanding what local people actually identified that they actually wanted. So yes, that seemed to me one of the sort of key foundations of the whole thing and the way in which the structure of the project and the structure of the planning and everything else sort of formed was based very much around those principles."* (Colin)

Scott and Salisbury also concluded that the Health Park project preceded, but shared the principles of the Healthy Living Centres proposed by the National Lottery New Opportunities Fund (NOF). These include:

- A holistic view of health, recognising that health is determined by social, economic and environmental factors, as well as individual lifestyles.
- To involve multi-agency cooperation
- To be set up in deprived areas, aiming to reduce inequalities in health
- To be set up in partnership with local communities who must be involved in determining needs and in all stages of planning and implementation (Scott & Salisbury, 2001)

The Health Park later succeeded in getting funding from NOF for a Healthy Living Centre (HLC) on the site. Once again, local people played a major part in the development of the HLC, including the appointment of staff and the services to be provided in the Centre. The Health Park also became important to the Knowle West Neighbourhood Renewal Strategy, coordinated locally by the Knowle West Development Trust, a locally run and managed Trust formed to help regenerate the areas, which adopted health as one of the themes for local action. As a result, a Health Action Group, including representatives from statutory and voluntary sectors and

from the local community was established to identify health priorities for the area.

The Health Park now includes the new William Budd Health Centre, an NHS Walk-in Centre, a Healthy Living Centre, a community cafe and a Kidney Dialysis unit, set in extensive grounds with views over the City of Bristol and outside space for walks, games, BMX and gardening.

In reporting the case study, I will describe three phases of development, the initial phase when broad strategies were being identified, a more detailed and difficult middle phase and the later phase, which followed the construction of the health park, when issues of service provision were more to the fore. Following the historical perspective, I will examine some other issues that arise from the data, including the nature of the partnership, the "career development" of the key local participants, the role and attitudes of local workers and issues of power relations.

7. 1 Partnership Working in Knowle West

First Steps: The beginnings of the Health Park

At the beginning of the health park planning process in 1995 or 1996, Karen and a few like-minded people from a variety of backgrounds developed ideas for a different kind of health centre that would meet local needs. Individuals were very important in the initial stages of development. Informants mentioned the same names over and over again as influential. These people shared the view that the community should be a full partner in any regeneration of the area and that there were opportunities for taking a wide view of health that encompassed well-being as well as curative medicine.

Common to these few people seemed be their willingness and ability to work both with the Knowle West residents and with the professionals from the statutory sector, even though that may cause problems in their own organisation. Karen describes a Health Authority Director *"shouting at me…'what do you think you are doing, tell social services; primary care that's our business'. To me it wasn't, it was joint business but she thinks that I went too far out of the corporate pond"* (Karen). These people, able to communicate effectively at the local level and the strategic, span the boundary between the two. In the initial stages, they were easily identified:

> *"Karen and Mike and Harold were out in front – rightly – and there were the public meetings and the events and so on where they had to speak to larger numbers of people in all sorts of different places and therefore their role was critical because at one end of the scale they were convincing chief execs and so on to come along with it and at the other end they had to effectively communicate with local people and make sure that they were clear that their views were going to be taken on board, they were going to be listened to properly, and we were going to do things a different way."* (Brian)

Like several others interviewed, Brian identifies key people at the beginning of the project. These (*"the band of brothers"* as another informant terms them) were fairly senior people in health and local authorities or in the voluntary sector who were involved in strategic decisions, but they were also people who had the personal skills to communicate with the professionals and the residents and established a credibility with both. Other supportive professionals, without achieving the same kind of involvement learned to *"take off the suit"* (Brian), acknowledging that working in Knowle West required a different approach – and a different look than engaging with professionals in the office.

> *"....we wanted... to show that we meant business and we weren't going back to where we'd been and we were pleased that a decent number of local people came along to the meetings and actively contributed and didn't feel, you know, that it was the suits or anything like that and that they can communicate with us and personally built up quite a rapport with a number of local people and they*

were confident that they could ring me and have a chat over the phone and tell me what was going on and they'd see me about. And I'd already started to cast off this image thing that goes with my profession – this suits thing – and that helped to break down barriers as well" (Brian)

These things were recognised also by local participants who valued the fact that the professionals were prepared to work with them in Knowle West:

> *"Harold used to come and talk to people and it didn't worry him about coming to talk to me in my living room with other local people, he didn't have a posh office downtown that we had to go to go down there, he actually came to where people was and if we said we didn't like that roof or didn't like that, he went out of his way to change things, he was really nice approachable person."* (Maggie)

At this stage comparatively few local people were highly involved, holding meetings in their living rooms and interviewing the architects, but those who did learned that in this project, they could work with the professionals, and that they had a voice and that they were being listened to and taken seriously.

> *"...they seemed to realise that people were listening, people valued what they were saying and they...I think they would go away and bring opinions back, because they were residents and felt to be fairly representative, people did listen to them".*(Anne)

However, those who were actively going to meetings, whether in living rooms or offices downtown remained the exceptions, most of those who took part were passive participants, many of whom were attracted by fun days and health fairs or through day-to-day contact with the Health Park as patients or workers, but not involved in meetings or participating regularly. Some of the most active of local residents put this down to the way in which the meetings were run. Kelly's conclusion is that *"professionals don't speak the language of local people; it can be a bit intimidating."* (Kelly), while Rita's view is similar:

"I think I know that's what frightens people. They are frightened to speak in a group, if the people may be more clever than them so therefore what they say is considered to be rubbish. I know that for a fact for when I try to get people at meetings, that's what they've said. I can't speak up and I don't know enough about it and you know, it's hard to get to convince some people that they know everything about it's the professional people that don't." (Rita)

Among health professionals there was not universal support for the involvement of local people. Some were sceptical about involving local people finding the concept of user involvement difficult to grasp, others thought that it was just a fad or felt that those involved were not representative and had their own agendas or that the plans were unrealistic.

> *"...some people actually wanted to distance themselves from it because some people felt...the concept of actually developing certain services out there was never going to be successful...you just wouldn't get consultants going to Knowle West"* (Colin)

For those who felt this way, local people were patients and they came to the services, not vice versa. Some informants saw GPs as able to have a similar influence on the Health Park. They could make or break plans:

> *"GPs still sort of end up holding that sort of level of power that, even though you probably don't appreciate that they have, but if GPs don't support something its very difficult to actually get it off the ground"* (Sandra)

Despite these occasional difficulties, many professionals working in Knowle West supported and worked hard to make the health park successful. The emphasis on changing the face of services was kept up by the creation of a more formal management structure including a Steering Group made up of local representatives and professionals and a high level "Policy Group". The Policy Group was initiated by the Chief Executives of the health and local authorities. This enabling group meant that change could be pushed through despite the reservations of middle managers and local workers. On this group also were one or two of the

most active of local people. The role of this group was described by the Health Park Manager:

> *"I used to see it as a place that would unstick things for us, because we were working in a sort of different way and a sort of a partnership. If I went back to them and said, officers at this level in either the Council or the HA weren't sort of helping what we were trying to achieve then they could unstick things."* (Mike)

Within the Steering Group was a broad representation of the partnership, which aspired to, but never has achieved a majority of local representation,

> *"In practice we have found that influential local people don't always want to be coming and sitting around tables talking all the time. Some do and some are very good at it and some want to be much more down and doing things."* (Mike)

The role of the Steering Group was to make nuts and bolts decisions. There were local workers involved, both in their service management roles within the statutory authorities and in support of the local representatives.

> *"Most of the activists who were involved on the steering group we would know through working on different projects so from that point of view, it was very much a big part of Knowle West work really and if I wasn't directly supporting the steering group, I would be supporting a group of people to make sure they felt confident about being on the steering group".* (Donna)

Local participation in the Steering group was less than had been anticipated but in the Policy Group, Rita was a full member acknowledging the three-way nature of the partnership. Unlike many local people, Rita was willing to "sit around tables talking":

> *"I don't know, we are sort of blessed on the health park with having some fairly gifted people really and Rita is one of them. She has been on a number of local boards and she is a very intelligent and competent person she had already been part of the interview panel and worked with those chief officers in the project, so it was quite easy for her really."* (Mike)

The management structure was not the only place where there were local residents taking part, a number of groups were formed to take on

individual practical tasks including organising a children's competition to design the gates for the Park and designing the layout of the interior space in the health centre.

So as the planning phase moved into making the Health Park a reality, local citizens were involved in different ways and at a number of levels. They had participated in the initial thinking and in the planning and some had taken on the challenge of becoming familiar with the meetings culture of health service management.

Moving on: the middle phase of development

As the building moved on, other people from the health service and local authority became involved and the "band of brothers" began to take more of a back seat. The decisions became less strategic, more mundane perhaps and those involved in making them were those most affected by them. A William Budd patients group began to meet with local workers to decide on plans for the public areas in the health centre. For some time things progressed well, but in the course of discussions involving local people and staff about the reception area in the health centre, the difficulties really started to make themselves known:

> *"They were choosing the seating and colours and floor coverings and things like that for the reception area which the user group were heavily involved in and because the receptionists were as well and they had this huge disagreement. The receptionists wanted it (the reception desk) as high as it was possible to have it and the users wanted it as low as it was practically possible to have it... the perception of the users was that staff wanted to hide behind these barriers...and so the users didn't want the barriers and the receptionists did"* (Anne)

The local representatives on the group were livid, after building a working relationship over a long period

> *"...they wanted to put them behind perspex and local people were really furious and said well Christ we have worked together for two and a half years to put this together and you are still telling us you want to be behind bars."* (Donna)

The disagreement led to even worse conflict when one of the doctors intervened:

> *"One of the doctors said...If you were faced with all these criminals coming in all the time, you too would want a proper bit of security. Now he said this at a meeting with local residents in it, including two lay members of the PCT who just ate it for breakfast as you would imagine...but word spread like wildfire and it was the collapse of the patient consulting group"* (Donna)

A complete breakdown was averted by the CHC's mediation, but what had been lost was the much of the trust that had been built up by the early work. One of those most involved, Rita describes the effect on the group as confirming the worst fears of some who took part:

> *"There was a good dozen people or more who refused to come back from there and just said 'there you go Rita we told you that would happen'".* (Rita)

The relationships built up by the early involvement were insufficient to withstand these problems and the lack of trust of statutory services quickly resurfaced, but these relationships had been built with the "band of brothers" who were able to act flexibly, without the concerns of the everyday. It was the reception staff and managers of the health centre that had been more involved at this stage, but it was the same local people who were involved. These were decisions that affected the workers at the Health Park, rather than the "band of brothers" but the health centre staff did not share the vision of planning with the community and they had not been involved in the early discussions:

> *"... it wasn't actually about a reception desk at all, what the conflict was about, I think, and in fact some of them have said it because I have talked to staff in retrospect, one or two is that no one was kind of pitching for them and they felt... like the bottom of the heap with no power."* (Terry)

The fragility of the participation of local people was exposed and it happened in Terry's analysis because in empowering the citizens, the band of brothers had unwittingly disempowered the health centre staff. Or perhaps what it had done was to enlighten them to their lack of participation in decision-making in the past.

At this stage also, the opportunity arose to bid for money from the New Opportunities Fund to build a Healthy Living Centre. As we have seen, the philosophy of the Healthy Living Centres was that local people should be heavily involved. Maggie describes what happened when a NOF official visited Knowle West:

> *"Rita and I was part of the group of people that was talking to NOF, the new opportunities fund and we invited the top man – and he doesn't usually come out, but he did come out and Rita and I took him to Filwood café and we took him all around Knowle West to see what local people have been doing and were doing. That bloke was so impressed and we didn't have nobody else, no health officials and nobody from the Council, it was only local people and that bloke was so impressed I think he gave us every penny that we asked for and they normally knock off so much for whatever, but he gave us every single penny on the condition that everything that local people wanted to be in that HLC was going to happen. So whether it was that we wanted to dye people's hair pink every Tuesday, if that was what we wanted, that was what we were going to have and that HLC had to tie in with whatever was happening around Knowle West."*
> (Maggie)

In this instance, it appeared that the direct input of the local activists themselves that made the difference, and their views were taken wholesale by NOF, or were they? Another informant, Simon offers a slightly different version, again identifying the important role of intermediaries:

> *"We are a product of local people's views, local groups' views that are then synthesised into an acceptable form that they can then be read by funding bodies such that major grants can be secured. To what extent is it a synthesis or is it a form of editing and you know controlling and that is the bit I am unsure of"*
> (Simon)

Another point of view was that there had to be others involved in identifying complementary therapies as a priority for local people:

> *"...my immediate response was people saying that they want aromatherapy and acupuncture is because some middle class person working with them thinks that this is what they should want"* (Denise)

Denise's comments appear patronising and to underestimate the understanding of local people, as they are, but there is a deeper meaning here. She is hinting at her analysis of what is actually going on: manipulation of local people by another professional group. This is the community workers whose interests, according to Denise, are different from those of the health service managers and do not serve the real interests of health in Knowle West.

Simon makes almost the same point, that it is the community workers who challenge the prevailing view, but his specific concerns are less important if the actions of the intermediaries, or boundary spanners (Williams, 2002), only articulate the views of the locals. While there is the opportunity for changing, sanitising proposals to make them fit with the necessary criteria, Maggie clearly recognises the services delivered as those that they told the "top man" they wanted. And community development workers like Kevin and Sarah stress that for them success is seen in the activities and achievements of others such as when:

> *"Local people passionately and coherently state their case for what they want to see happening, with people who make the decisions and have their hands on the purse strings, and get taken seriously."* (Kevin)

The success of the NOF bid was also a cause of a certain amount of conflict with local professionals, in this case the Health Centre GPs who objected to the focus on complementary therapies to be offered in the Healthy Living Centre, which were of unproven benefit.

> *"On the healthy living project, because the doctors all wanted it to be healthy eating, diet, exercise based and local people wanted it to be stress related, managing stress and the effects that that has on peoples' lives and health etc...and there were quite a lot of...it really got quite edgy from time to time*

> *between local people and...or the views of local people and the views of doctors, because doctors were taking quite a traditional route and actually quite a lot of the local people who were key in that development were very interested in complementary therapies and all that sort of stuff to kind of support people where they were at. And some of the doctors were quite kind of...err I don't think that's a very good idea."* (Donna)

Others saw this as local people asserting their views over the health service professionals, promoting their own choices and their definition of evidence over the medical model dependent on scientific testing.

> *"Men tend to...we talk about internalising stress. We tend to deal with it in other ways and particularly you know, drinking and violence and generally it comes out in ways that they don't identify as being part of stress but women seem to be much more ready to identify the problem as being stress related. The only problem is that the only option they used to have to reduce the stress where chemical options and so...working class women from Knowle West started to say that 'I am not sure I want to be constantly on this prescription and I really like having a massage'. And it's not so much about saying that 'I think this massage is going to reduce my stress' but it's just people being open about saying 'I really like that' and 'I like aromatherapy ' and 'I really like this because it seems to relax me, and gives me a good night sleep' or 'make me more tolerant with my kids'. And that sort of thing, and so it was definitely didn't come from us it was coming absolutely loud and clear from local residents that they wanted to see this as part of the many of things that could be provided by doctors. And the doctors didn't agree with this at all. They said 'no evidence, no'. I suppose that is a very big cultural thing for doctors who see themselves as locally based scientist in some way or delivering a sort of scientifically based (service)."* (Damian)

However the Healthy Living Centre was built and focuses on stress management featuring complementary therapies, delivered in part by local people. And as time has gone on, as a number of informants report, GPs have begun to refer patients to the alternative therapists, rather than prescribe drugs.

Despite these conflicts, the Health Park was established and attention turned to the services that should be provided there. At the same time, it also became central to the Knowle West Neighbourhood Renewal strategy.

Third phase – prioritising services

The most recent phase is exemplified by the Knowle West Health Action group and their plans for "bending mainstream services", that is using the money to develop services that more closely meet local need, under the banner of neighbourhood renewal. This group, made up of a stable group of workers from local authority, the health service and the voluntary sector was joined by a group of local people who attended meetings sporadically, but with effect.

> *"One or two of the local people are quite strong characters, I think it has made a marked difference when they have been present and challenged us about what we have been focusing on and what is a priority."* (Fran)

And from observation notes, it is quite clear that when there is more of a local presence, certainly when key local people such as Maggie and Rita and others attend, that the discussion focuses more on fundamental questions of how money is allocated and what the priorities are, rather than the process of how mainstream services are delivered in Knowle West which feature strongly when the group is mostly made up of Council, health and voluntary sector workers.

This suggests that the workers involved are more concerned with implementing decisions than with making them and are looking to the residents to take the lead in developing priorities. This was confirmed to an extent by the decision to hold an open forum at which a greater number of local residents could identify their priorities for health action.

What emerged in the Health Action Group was that local people were willing to challenge the agendas that were set by the professionals. For example in the July meeting, the first item on the agenda was a report on which groups had been funded by neighbourhood renewal money. The report was barely begun when one of the local representatives began an

attack on the process of allocating money, in particular the time allowed to discuss individual projects and the lack of local promotion of opportunities for funding. Other local people and some boundary spanners supported her and confirmed the local unease about the process so, by using her opportunity to speak; she was able to shift the discussion from reporting which projects had received funding to how decisions were made and to challenge senior staff from the City and health service to justify their actions. (Observation notes, Health Action Group July 30, 2001).

In general, local people who attended the action group meetings criticised them as boring and unproductive. Kelly describes her experience at similar meetings:

> *"I gets a bit frustrated...they just seem to discuss the same things over and over again...they ask us how we could get more people involved and then nothing happens and we're back to the same old things..."* (Kelly)

The process for involvement offered by the statutory authorities in this case did not engage local people. Fran, a public health manager recognised this but was perplexed:

> *"...my impression is that local people have been quite disillusioned. They appeared in numbers at a very early open meeting – and appeared at beginning meetings of the health action group – the health and well being action group...and then disappeared. And I...linked with Mike and others to say what is happening, this is turning into an agency group and we are in the words of Maggie boring local people – and we didn't understand why, we understood that they weren't present, that they were voting with their feet and not coming to that meeting."* (Fran)

Sarah, a community worker with the Knowle West Health Association, a local voluntary group and a member of the Health Action Group had experienced a similar lack of interest in her steering group and offered and explanation as to why things were going wrong:

> *"It needs a sea change in the way the process is organised to ensure maximum user involvement. Formalised meetings will not appeal to local people who have*

never experienced doing things this way, and why should it be the template?" (Sarah)

The open forum organised to identify health priorities did use a different approach. People were brought together in a fairly informal way. They were given information, a bite to eat and offered the chance to ask questions and to indicate their preferences by voting. Fran found the meeting frustrating and chaotic, while others found it interesting and entertaining *"an imaginative workshop...an enjoyable way of looking at the health issues."* (Kevin)

The dominant approach to involvement remains through formalised meetings. While in some settings this approach could be seen as protecting the less powerful participants, through rules of behaviour and recordkeeping, people from Knowle West are clearly intimidated and frustrated by a process that is foreign to them. In McKie's (2003) terms, it is an administrative barrier. The formal rules and conventions may be second nature to those from the statutory sector, but appear unfathomable to local residents. Initially at least, local people assume that the "professionals" *"may be more clever than them so therefore what they say is considered to be rubbish."* (Rita) Some, like Rita, have adapted to it, but it seems to take a significant amount of time and effort. Sarah, in trying to organise a community project had adopted alternatives that helped to engage her Board, but in this case, the statutory sector stuck to the traditional models. Most of those who do persevere and continue to be involved seem to come with a personal agenda, often a health problem, which spurs them to continue.

A similar theme was picked up in interview by Maggie, who described her approach to participation in meetings and how she was able to turn it to her advantage,

"we used to call it the beast and the beast was half controlled by health and half controlled by Council and one wouldn't move without the other and it was a really, really difficult job to make them both move the same way. And they were frightened to give an inch. It was really difficult to get them walking together at the same pace, down the same road... It is almost impossible without the ingredient of local people making them behave themselves and do what they are supposed to do" (Maggie)

Those who make this transition need significant support to do so. It is the boundary spanners, or what Karen called *"boundaroids"* who provide this. Whereas in the early days, it was the "band of brothers", in the middle and later periods, once the Health Park was in operation, it was the community workers who fulfilled this role. Maggie is quite clear,

> *"...we was lucky as we had one from health which was Mike and one from the council as you call it Donna and she worked exactly the same way was Mike and even if we had a councillor at the meeting and they are Donna's boss, she would tell them to shut up and let us speak. So they really was on the same wavelength and it was to our advantage."* (Maggie)

Maggie's view of Donna, a council employee, and Mike who was employed by the NHS was that they were not like others from those organisations. Others, like Sarah and Kevin work in a similar way, putting the views of the local people they work with above those of the organisations who pay them. Sarah had recognised this after having been in her job for several months:

> *"I'm a community development worker, so I'm meant to be involving the community, therefore I'm not going down there to make health better, it's all about encouraging local people to be involved in that."* (Sarah)

In this 'mature' phase, involvement seems to have been accepted as a fact of life and for some health service managers and professionals, it seems to be valued. The number of participants remains small however although the number of opportunities for taking part is growing.

7.2 Partnership and power in the Health Park

From the beginning of the health park project, there was agreement among partners that community involvement was an essential part of developing the facilities. Those who developed the concept, the "band of brothers" shared the aspiration that this should at the centre of the project and that it should adopt a broad, social model of health. (Dahlgren and Whitehead, 1982)

Where involvement did happen, it took a number of forms. Most visible were the involvement of people in solid parts of the Health Park, like the children's involvement in the design of the gates and participation in large scale events such as the health fair and the healthy action group forum. These were primarily indirect forms of involvement, where links to decision-making were unclear. Estimates of the number of people who took part in these events vary widely, but it is clear that they were well supported by local people and that they succeeded in publicising the health park and gathering local views. Direct participation in the steering and policy groups brought local residents into decision-making forums, but these were open to only a small number of people.

Initially in these formal groups, local people were at a disadvantage and were frustrated and bored by the slow progress. Once they began to learn and sometimes to challenge the 'rules' of participation, they became effective in promoting local interests. In the case of the health action group, they tended to become the focus of the meetings and to rewrite the agendas and alter priorities. It was local input for example that altered the direction of policy from smoking and heart disease to drug misuse and treatment in the health action group. Their action in the group setting was then endorsed by the open forum (Observation notes, Health Action Group September 18, 2002).

Residents of the estate who participated at this stage intuitively recognised and subscribed to the social model and believed that no development could be successful without their participation. The local authority also recognised the importance of community involvement in neighbourhood renewal, especially as it became central to best value and regeneration policy but there is little evidence that health service organisations were completely in tune with policy emerging from outside the Department of Health. For these organisations, the principle of local involvement seems to have been limited to individual, rather than corporate commitment.

While local people were involved in a number of different ways at various stages of the project, there were a number of important decisions that were taken without local residents' participation. At the very start of the project, a Renal Dialysis Centre was sited at the health park. The justification was that a site was needed at short notice and the space was available. Local people were neither involved in the decision to site the centre, nor in the running of the centre, which is a public-private partnership.

Donna reports Rita's comment that in deciding to locate the Renal Dialysis Centre at the health park without significant local involvement, the NHS had "got away with it this time", suggesting that she had less than complete trust in the commitment of the health service.

A second example was the decision to build an NHS Walk-in Centre on the site was also taken without significant local involvement. The decision taken at short notice to meet the Government timetable, rather than within a consultative planning process. What NHS managers had done in this case was to extrapolate from what they knew of local views as a walk-in centre would provide a service that people had said they wanted.

These examples are of decisions taken at short notice, when there may not have been time to meet local residents or fully involve them in making decisions. However, there is also a question as to whether there was real involvement about services to be provided in Knowle West. All of the informants spoke of the meetings held to decide on the internal look of the health centre, but few mentioned local participation in deciding what services were provided by the practices. One informant, a GP actually suggested that *"things like the more technical stuff about rooms and treatment rooms was left to us really which was sensible."* (Tony).

Donna also notes the lack of opportunities for involvement in decisions about health services. The nature of primary care in the NHS is that most services are provided by general practices, which are small independent private businesses. Services are provided to the NHS under a nationally negotiated contract and despite the recent growth of corporate primary care organisations and processes of bureaucratic accountability (Harrison & Dowswell, 2002), practices retain choice over which services they provide.

Knowle West is an active community. Local people know the ropes about user involvement and have been very influential in getting various projects off the ground. However, the Health Park was viewed by some of these more proactive community members as "alien" territory, more to do with illness than health. A more recent development, but with similarities to the health park is "The Park", an education and enterprise centre, located at the site of another closed secondary school on the estate. We conducted a focus group with people involved in work at The Park.

> *"...many go and see the doctors...not really anything else... I think the health park is when your sick. The Health Park is there like when it was in Leinster Avenue. I mean you went there because you were ill, you wanted to see a doctor and I think the* (Health) *Park works the same way...when they first started it there seemed to be a lot of energy coming into it...*(now) *its not reaching a*

> *wider...there's no reason to go there. You wouldn't go there and sit out and just enjoy it"* (Focus Group at the Park)

On the other hand, they felt that The Park was different in the perception of it as a space for local people.

> *"Well, we actually asked the locality what they wanted here...and we based it around that...then of course the TV people came in* (Channel 4 films "Teachers" at The Park)*...we still keep the premise that we'll try it and sometimes it doesn't work...we try to welcome people in and make them feel that they belong. Some people come for a cup of coffee and they stay to take a class, it's that kind of atmosphere"* (Focus Group at the Park)

The Park is run as a business, locally owned, which rents space to other businesses and runs the school as a community education centre. In a sense, it fulfils the vision of the "band of brothers" for sustained local involvement in controlling a space for giving access to skills, information and services. However it may be that it could not have happened without the Health Park altering the statutory agencies' perception of people in Knowle West.

The drive for local involvement in the health decision-making represents an attempt to develop a more pluralistic process, to reduce the dominance of the medical profession and local service managers and to increase the influence of other stakeholders, including local people. The involvement of local people in the design of the William Budd Health Centre, in the development of the vision for the health park, in the establishment of the healthy living centre and in developing priorities for neighbourhood renewal illustrates that on a surface level at least, the project succeeded in developing a more plural process. A claim of those sceptical of the involvement of local people is that their views are not representative of those of most people on the estate, or that their agenda is personal rather than that of the community. What evidence exists suggests that those who participate directly in decision-making do reflect local concerns as shown by the Neighbourhood Renewal Unit survey (Bristol City Council,

2002) and are descriptively and symbolically, if not formally or statistically representative.

From the perspective of the Arnstein model (Arnstein, 1969), some of the involvement in Knowle West reaches the level of full participation or partnership and perhaps even citizen control. However in other instances there was little participation. There are issues from which local people have been excluded, including decisions over the Renal Dialysis Centre, Walk-in Centre and about the services provided at the health centre. Some of these issues are central to the core business of the health centre or the local health service, while some of those where there has been most involvement are more peripheral. If we consider Skelcher's model of involvement (Skelcher, 1993), some of the issues where there was least involvement like the services to be provided in the health centre or by the local health service are strategic or even structural, challenging the dominance of health services. On the other hand, many of those where there is most involvement, including design issues for the waiting rooms are more peripheral to the interests of the health service.

This may be an indication that the involvement, while not exactly "window dressing", was permitted only when there was little impact on the fundamental interests of the statutory authorities or professionals. There is some evidence that this is the case. Karen's story of her encounter with her director and Donna's view that

"People like X in the health service are saying well I am really sorry but I'm forty million pounds overdrawn, you can't have any money. And she's not consulting with local people to say given the set of priorities what would be your priority for this money in this areas, she is making a decision based on what the government is telling her she has to do and various other things which excludes that because it is seen as periphery. It is seen as window dressing I think, even though it has achieved such a lot" (Donna)

The role of the Policy Group, initially as enablers transformed over time into more about control of the project. Change in personnel was inevitable as structures changed, but it also led to change in function:

> *"what's happened is over time is that obviously we don't have Avon Health Authority anymore, we have the Primary Care Trust, we don't have a Chief Executive at Bristol City Council...so now we have somebody else on (the Policy Group). The people and it is all bout people who are on that now do not understand their role in that sense anymore. They don't see their role as enabling something to happen"* (Damian)

Changes in approaches to policy also had an impact as the local authority appeared committed to engaging local people as partners. One of the Council's Directors told me:

> *"...the council doesn't go back to Knowle West and say well we're the Council and we are so much bigger and more powerful than you that you have just got to do what we say, it is much more of a dialogue"* (Lesley)

Whether local people would agree with that assessment is doubtful. Maggie was scathing about both the Council and the Health Authority/PCT who were unwilling to engage in real discussion, claiming that their hands were tied by the rules and policies that they had already set:

> *They are all the same...they are all the same. They all have their...they call them policies. I think they are little boxes to hide behind. If anything is a little bit out of the norm or difficult, they stick a policy in the way and say we can't do it because. All of them, there are no exceptions.* (Maggie)

The clinical professionals who work in Knowle West took little part in the process of involvement, despite their local knowledge and day-to-day contact with local people as patients. However as Sandra reported it is the GPs who have most influence over the services provided at the health centre, partly because of their contractual relationship with the health service, but also because of their unique position as the respected authority on health issues. Professional power, particularly medical power is an example of how power can be exercised effortlessly by the powerful

who construct and control shared understandings of health and illness. The role of doctors in decision-making about the health park was implicit and local people and managers alike accepted this role and in general made decisions that the GPs would live with. Some local people did express a simmering resentment of the lack of community involvement of local GPs,

> *"...you only ever see the doctor in his "little box" or when he comes to your house when you are sick, but if you ask anybody, do they see a doctor socially, walking around Knowle West, going in the shop, in Tesco's, they will say no we don't and doctors never go out on the streets..."* (Maggie)

But others offered a more common view of their expectations of doctors:

> *"...he sat down and explained things, like what I needed to do, what he needed to do and within like about an hour he said 'like I rang up our specialist at the BRI, this is what I need to do, I've made all these arrangements for you, if you find there's a problem let me know. And if you can get up here I would be grateful, if not we will arrange some transport and stuff like that for you.' Now all that was done, and I thought that that was the sign of a good doctor."* (Focus Group, health centre)

This informant expects the doctor to offer expertise and make the decisions about what he needs in terms of treatment and makes the care decisions without consultation. The ceding of choice and power to the doctor is something that the informant is completely happy with, while the doctor also accepts his/her role in the exchange. The informant and the group (none of whom had participated at the health park) did not consider the role either of the doctor or of local people in determining health policy, nor in any collective relationship.

One place where there was a challenge to his hegemony was over the Healthy Living Centre, where local people, apparently without the input of anyone from the statutory agencies challenged the medical model of health care. They showed significant dissatisfaction with what the practices were offering in terms of responses to stress, preferring

complementary therapies to the prescriptions offered by the GPs. By convincing the NOF representative of their case, they were able to determine the services provided in the healthy living centre, basing them on complementary, rather than drug therapies to help people deal with stress. The lack of evidence of effectiveness for these therapies was seized upon by the local GPs to challenge them; nevertheless, they were established successfully at the healthy living centre. Similarly, when involved in deciding priorities for the Neighbourhood Renewal Health Action Group, local people offered a markedly different view than those of the health service managers, universally preferring to stress services for drug users, rather than smoking cessation and healthy diets, which they rationalised as more important for an estate in which drug use lay at the root of wider social problems like crime and the fear of crime. In both cases, they were not willing to accept the health professionals' views of their needs, which they saw as too narrowly drawn.

What was different about the Healthy Living Centre development and neighbourhood renewal is that the funding originates not from the NHS or the Department of Health. Health Living Centres were funded from the National Lottery. The criteria for funding healthy living centres stresses a holistic or social model of health which is more compatible with local citizens views than those of the NHS. So support from the funding body is less concerned with what works in narrow medical terms than what people want locally leant influence to local opinions in a way that had the HLC been funded by the NHS would not have happened.

The relationship between the NHS and local people has never been based on notions of local accountability, whereas the relationship between NOF and applicants specifically mentions responsiveness to local views as criteria for funding.

Older models of giving account to local people by the NHS were derisory: *"my perception has always been that you ask people and consult people, but you really don't have to take it seriously"* (Colin). But in Knowle West, the approach was supposedly for people to be represented in decision-making forums, as Mike said as a three-way partnership. If this was indeed the case, local representatives were critical of the process. Kelly for example suggests a persistent mistrust of decision-makers and concludes that decisions were shifted away from meetings which were attended by local people.

> *"...it seems like they are kind of listening, but then they go away and take their own way anyway. I'm not sure that they are listening, it's kind of half and half...they don't seem to be telling us everything, it's like they are only letting on part of the story."* (Kelly)

The complex network of organisations involved in Knowle West and specifically the health park makes an assessment of the processes of accountability very tricky. Sullivan (2002) suggests that models of accountability that are most appropriate in the context of the network of organisations should focus on the extent of dialogue with stakeholders. In the case of the health park, dialogue with local people was a fundamental feature of the early phase of development and to an extent has been maintained through the partnership structures such as the Policy and Steering Groups and other initiatives such as the Health Action Group. However, increasingly, the Policy Group, which Mike called an enabling group has, according to Simon taken on *"responsibility for the future shape and direction of the project"* (Simon). While local participation is nominally guaranteed, Denise's assessment is that local participation has been sporadic.

While early in the project, the agenda was held jointly, though influenced by the philosophical position of the "band of brothers". In more recent times, when the agenda has been more central to the core business of

health service organisations, the ability of managers and strategists to control the agenda, the form, the location and the time of forums where decisions are made is an example of their exercise of power of "non-decision-making" (Bachrach & Baratz, 1970). Managers are able to control the content of agendas and use rules and procedures to exclude local people who are unfamiliar with "meetings culture". However, this top-down power is dependent on the compliance of local people. Once local people who are willing to continue to participate begin to use the rules and procedures against the statutory organisations *"...this last time, I got really fed up and let them have it...they just never seem to get on with it and do things."* (Kelly) exercising a positive bottom-up form of power (Foucault, 1994; Hindess, 1996; Gilbert, 2003) Unlike the repressed interest of the community in Alford's model, (Alford, 1970, North & Packham, 2001) the community is able to have an impact on heath decisions. Their participation in decision-making forums can be decisive, particularly within partnerships when there is disagreement or uncertainty among the statutory authorities.

The activity of the boundary spanning workers, the community workers who have credibility with the statutory authorities, but who work closely with local people, is an enabling influence (Abelson, 2001) which secures local participation through advocacy and support, which builds skills and competence in the meeting culture.

For those local people who are able to endure the meetings, they are able to exercise significant power, especially when they resist or subvert the "meeting culture". Observations at health action group meetings show that when they were present, local participants were able to re-shape the agenda, prioritising, for example treatment of drug users over smoking cessation and healthy eating against the wishes of both health and local authorities. They often do this by calling on the rules and values explicit in the partnership agreements, which expressly call for local involvement.

Local and health authorities are then unwilling to be seen to go back on their commitment. In support, another local participant in the action group questioned whether the outcome of the meeting would be the same if local people were not personally present. They were supported by Mike, the Health Park Manager and a boundary spanner. (Observation Notes, Health Action Group June 30, 2002)

This demonstrates the ability of local people to exercise power within the meetings by drawing on the resources at their disposal. The resources include the experience of participating in meetings and being part of the early development of the health park, their use of the rules and conventions of partnership and the support of the boundary spanners. But for Maggie, the local participation was what made the partnership "the beast" function as it was they who forced the statutory authorities to make progress.

The extent to which this was a subversion of the meetings culture was confirmed by some of the professionals. For one planner, it was unfamiliar and disconcerting:

> *"I have to say if I look back...I am somewhat surprised and amazed to see what things have happened, given what felt to me to be quite an unstructured process and that was probably because we were breaking new ground, but it never felt very clear to me about what the remit of the various groups involved in the process actually were. It just felt that all the people were finding their way through a maze on the hoof without actually following some of the more traditional sort of planning processes"* (Colin)

Another, a local GP felt somewhat the same, yearning for a tidy process:

> *"the decision making process was awful...it was just pulling one way and another and people weren't prepared to make a decision and so it just went on and on and on. Where as if they just had clearly set out the remit of your group you would make recommendations to this body. This body will make the final decisions. You won't necessarily get everything exactly as you want it but it will all be put into a mix and that would have been much, much better."* (Tony)

In Knowle West, the process and extent of involvement changed as the project proceeded. In the early days, local participation was crucial to the project and those involved shared a view of health and local needs and were committed to maintaining local involvement. At this stage, the health park was peripheral to the business of the health authority and they were prepared to permit strategic decisions to be devolved to those involved. Once those people originally involved in the project began to take more of a back seat, those who were working with local representatives did not necessarily subscribe to the same perspective on health or have the same level of commitment.

7.3 Summary

At later stages in the development of the project, decisions moved closer to the core business of what was then the PCT and there was more reluctance on the part of the health service to allow unfettered local decision-making. There is however significant evidence that local participants have grown into the role of health service decision-makers and are prepared and able to challenge statutory authorities on their view of the priorities for health in Knowle West. This has been partly enabled by the developing neighbourhood renewal agenda which established partnership and local participation as major features of regeneration. Crucial to the ability of local people to take a full part in the decision-making process has been the activities of boundary spanning workers, particularly community and health development workers who are able to interpret the language of statutory authorities for local people and work closely with them inside and outside of meetings. This reduces the ability of the statutory authorities to regulate the involvement through manipulation of the form and spaces where involvement takes place.

The limited participation of general practitioners in the decision-making forums of the process of involvement does not appear to have reduced

their influence over local health policy. Their role and importance in primary care service provision, added to their independence and symbolic power in primary care policy means that they remain the dominant interest, particularly over service issues. However the success of local people in deciding on the services to be provided at the healthy living centre, a project funded by the New Opportunities Fund, rather than the Department of Health may indicate that the dominance of the medical profession has declined.

Chapter 8: "Sleeping with the enemy": User involvement in mental health services

8.0 Introduction

The third case study examines the area where the involvement of service users has perhaps the longest history and which was found in the survey to be where most activity was taking place. In this study, rather than concentrate on involvement related to a specific piece of work, I will more generally discuss the progress of user involvement in mental health services in a single geographic area. The study arose from two sources. On one hand, there was the emergence of a new form of provision of mental health services in Somerset, which merged the two statutory organisations who specialise in providing services to people with mental health problems, an NHS Trust and a Social Services Department. On the other hand, was the existence of a loose confederation of service users known as Speak up Somerset (SuS). This group was supported by, but independent of, both health service and local authority service providers. It was run by service users themselves.

I was interested in how these two very different organisations, the new Trust and SuS, would relate to each other and how a new organisation in provision of mental health services would develop at a time when there was increasing pressure from government to involve service users and the public in decision-making (NHE Executive, 1997; Department of Health, 2000).

The two previous chapters were based on the participation in health decisions by people as citizens, however although citizens have an interest in the provision of health services as stakeholders in public services and as potential users of services, there is an additional

dimension to the interest of service users, particularly those who are involved with services on a long term or ongoing basis. Apart from their personal interest in their own health, long term service users accumulate a significant stock of knowledge and experience of the structure and functioning of services. They experience services individually and their perspective on services is likely to be shaped by their personal experience of them. However, the ability of service users to participate in decision-making may be compromised by their current health, by the feelings generated by their use of services; by their feelings about those who provide services and the professionals they depend on for treatment. This chapter deals with the involvement of service users in mental health service decisions.

In mental health, there is a long tradition of service user organisation, related to, but independent of service provision. Drawing on the anti-psychiatry movement of the 1960s, the later development of clinical psychology and social psychiatry and the consciousness raising approaches of the civil rights movement, the mental health service user or survivor movement has grown since the 1970s (Peck et al, 2002; Diamond et al, 2003). The 'service user/survivor movement' describes the people who speak out individually and collectively for the rights of those who use or have used mental health services. It also includes local and national groups and organisations set up to provide mutual support or to promote the rights of current and former mental health service users. Group members and individuals may call themselves 'survivors', 'service users', 'clients', 'ex-patients' or use similar terms. The term 'movement' implies that these individuals, groups and organisations share some common goals and understandings of mental health (Wallcraft et al 2003). The service user movement offers an alternative view of mental health services to that put forward by the medical establishment which according to some writers represents a source of oppression for people in mental distress (Johnstone, 2001; Harper 2003).

Some writers view user involvement as a way to bring about transformational change in mental health services by promotion of self-determination and participation and speculate that it could be a way to begin the restructuring of the service so that it values and respects the knowledge and experiences of both service users and professionals (Diamond et al, 2003; Pilgrim & Waldron, 1998). Others involved in the service user movement regard involvement as co-option into an oppressive system against the interests of service users that reproduces the flawed notions of mental health that currently dominate (Wallcraft et al, 2003).

In 1999, the Department of Health completed the National Service Framework (NSF) for mental health services. Service users were involved at a national level in developing the NSF. Participation appears to have been haphazard, rushed and chaotic and those involved expressed dissatisfaction with the process and final document, even though there is progress towards some of the goals of the user movement (Wallcraft et al,2003). The NSF states that to *"involve service users and carers in planning and delivery of care"* is the first guiding principle underpinning adult mental health services (Department of Health, 1999: p. 4) What is less clear is what is meant by involvement, what its purpose is and what makes it important to improving care for people with mental distress (Diamond et al, 2003). According to Bowl (1996), there is a general confusion about the meaning and purpose of user involvement across mental health services as well as resistance among some who work in the services. Pilgrim and Waldron (1998) found an enduring strength of medical models of mental health was a factor that restrained the growth of user involvement, while Newnes (2001) reports that user views were often subjugated by dominant medical discourses.

This case study examines the extent, form and impact of the involvement of service users in mental health services in one County in the South West of England. It seeks to answer questions of what approach the Trust took to service user involvement, the extent of their commitment to the involvement of service users and whether service users were central to the development of services. It also seeks to examine the motives of service users in becoming involved, their expectations of involvement and the extent to which their expectations were fulfilled. Mental health services in Somerset were rationalised in 1999 through the development of the Somerset Partnership NHS Trust, which brought together services previously provided by Somerset County Council and the Avalon NHS Trust.

Evidence has been drawn from interviews of service users and service managers (see Table 8.1), documents produced by the Trust and service users themselves and observation at meetings of one of the main service user organisations in the county. The evidence gathered for this research is supplemented by material from other contemporary research in mental health services in Somerset and across the UK.

Somerset is a predominantly rural county, with population concentrated in several small urban areas. The main centres of population are Taunton, Yeovil and Bridgwater although there are a number of market towns such as Wells, Glastonbury, Street and Chard and a tourist orientated coastal strip stretching from Burnham-on-Sea to Minehead. Yeovil and Bridgwater are predominantly industrial towns, whereas Taunton, is the administrative centre and a market town.

In a study of the emergence of the Somerset Partnership Trust, Peck concludes that Somerset has a hierarchical and paternalist approach to service delivery, born out of the patrician nature of the area (Peck et al, 2002). His study finds evidence to support this conclusion, particularly in

the existence of a "governing elite" within local government and health service, but it might more accurately be described as corporatist rather than patrician approach to local governance as all of those involved are in appointed or elected, rather than inherited positions.

Table 8.1: Interviews and Observations Somerset Mental Health Case Study

Name Used in text	Personal role in mental health services
Sean	Regional Mental Health Service User Development Worker (Survivor)
Sandra	Mental Health Voluntary Worker (Survivor)
Paul	Mental Health Voluntary Worker (Survivor)
Roland	Mental Health Service User
Martha	Mental Health Service User
Owen	Mental Health Service User
James	Mental Health Service User
Martin	Mental Health Service User
Walter	Carer
Peter	Chief Executive, Somerset NHS Partnership Trust
Carol	Locality Manager, Somerset NHS Partnership Trust
Richard	Senior Manager, Somerset NHS Partnership Trust

Observations	
Speak up Somerset Meeting	Yeovil
Speak up Somerset Meeting	Frome
Speak up Somerset AGM	Glastonbury
South West Regional Users Group	Taunton

In public involvement in health services, Somerset is sometimes identified as a leader in the field as the Somerset Health Authority established health panels in the early 1990s to provide a public input into decision-making through focus group discussions of health service issues held in communities across Somerset with a demographically representative

group of local people. (Bowie et al, 1995). The panels continue to run regularly, with the reports made available on the internet (www.somerset.nhs.uk) . Although panel discussions prior to 1997 were not available for review, there appeared to be only one round of panel meetings that had discussed mental health issues, in 2001 when 12 panels discussed "attitudes and barriers to seeking help for depression and stress-related disorders". (www.somerset.nhs.uk, accessed July 24, 2004) None of those interviewed for this case study mentioned the panels.

8.1 Mental Health Services in Somerset

Mental health services in Somerset are provided by the Somerset Partnership NHS Trust and commissioned jointly by the local primary care trusts and Somerset County Council. When it was established, the Trust brought together funding from the Somerset Social Services Department and the NHS to provide an integrated service to clients across the County. It was established in 1999 as the first joint provider of mental health services in the country. User involvement was identified at the beginning of the Trust as an important part of the redevelopment of mental health services in Somerset. Service users were involved in the interview process for the Chief Executive and *"should participate at every level"* (Peter) in the structure of the Trust.

User involvement in Somerset Partnership NHS Trust

The mental health service user movement was already well established in Somerset when the Trust began operating in 1999, but contact with commissioners or providers of care was limited. Sean, a former user of services involved at a national level in Survivors Speak Out and MIND spoke vaguely of an Avalon Users Group (Avalon was the former NHS Trust) *"...or something like that"* (Sean) existing before the Trust was

established, but that *"...there wasn't the local...(contact with)... groups I could really identify"* (Sean). According to another informant, *"it was advanced in the sense that there was a whole degree of user groups and an organisation of user groups but they (the organisations that preceded the Trust) didn't know how to use them properly"* (Peter). One of the local user groups, "Speak up Somerset" (SuS) is a loose network of mental health service users that was founded in 1995 and has continued to meet roughly monthly and produce a newsletter that has been widely distributed to service users in the County ever since. Their newsletter covers national and local issues related to mental health and is firmly rooted in a social model of mental health. For example, Heyes, a service user from Somerset and a former editor of the newsletter concludes that the dominant medical model of mental health represents a source of repression of mental health service users, perpetuating the dominance of medical definitions of mental illness as deviance. He offers the user/survivor perspective as an empowering alternative with a focus on a radical change agenda that includes citizenship and rights (Heyes, 2002). One former service user was quite clear about the purpose of involvement with service providers.

> *"We...recognised that there were serious deficiencies in mental health services...it was the role of campaigning that eventually led us to seek entry or access into the various forums that the statutory sector were involved in. In other words, we wanted to influence, we wanted to bring about change, we wanted to create new services which were designed by service users for service users as opposed to those handed down from on high"* (Paul)

These expectations of change were matched by the comments of the Trust's Chief Executive. At a meeting of Speak Up Somerset in Glastonbury, the Chief Executive said that for him, *"The whole of the health service is changing round. The absence of users and carers (at meetings) now looks as odd as their presence did ten years ago"* (Observation Notes: SuS AGM, April 2002). However, from the service user community, there was more scepticism. Sandra, a survivor and

voluntary sector worker saw *"very positive signs"* but thought *"we are dealing with a staff within the professional side of the mental health field who are two-thirds incredibly conservative, hate change and exercise power...in an inappropriate way."* Peter agreed that clinical staff were not all on board, *"I could pick out a couple of consultants in our Trust that think this whole thing about user involvement needs to be nipped in the bud. They fail to understand that this bud is a bloody great tree!".*

The Chief Executive's view that everything had changed and Peter's *"bloody big tree"* of participation were not generally borne out by discussions at Trust Board meetings. A review of Board meeting minutes from the Trust website (www.somerset.nhs.uk accessed April 17, 2003) record no minuted discussion of public or user involvement in the previous twelve meetings.

If there was little penetration into discussions in the Trust boardroom during this period, there were other areas where the role of service users was acknowledged. Service users were given formal involvement in the commissioning of services through participation in the Joint Commissioning Board (JCB) and in area forums run by the local Trust managers.

Involvement also took place in less formal ways, particularly at local level. Carol, a locality manager spoke of an approach that encouraged small steps towards bringing users more into decisions about policy. For example, in planning group activities, *"...they set the agenda"* (Carol). This also led to participation in making decisions about local services around the development of an out-of-hours service that both arose from the group and was planned with them, much along the lines that Paul had suggested. For Carol, herself there were consequences as she *"got a little bit of a wrist slapping"* for beginning the project before approval was granted. Her view was that that was part of the job of a local group

facilitator, to advocate for the mental health service user and to stretch the rules if necessary.

Strategic Plans developed by the Trust also acknowledge the role of service users in planning services. The Trust's overall strategy set out its position on user involvement as inclusive, seeing service users as one of a number of stakeholders in the Trust.

> *"We have been able to move beyond social services/health partnerships to stronger relationships with user groups, carer groups, and agencies such as housing, education and employment. Too often in the past they have been left out whilst health and social services try to sort out their relationship. A strong health and social services relationship in Somerset has allowed us to give the time to ensure a wide and inclusive partnership of relevant agencies."* (Somerset NHS Partnership Trust, 1999)

In its Clinical Governance Strategy, the Trust claims to *"enhance the ability of service users and carers to have direct input into the targets of quality improvement plans"*. (Somerset Partnership Trust, 2003: p. 3) It considers user involvement to be an area of strength for the Trust, however the detail of the plans for involvement (www.somerset.nhs.uk, accessed April 17, 2003) are limited to promises that *"user/carer representatives will be invited to comment"* and *"kept informed of proposed new standards"* and at a local level, the planning process *"will require (that) units talk to local users and carers"*. These are indirect forms of involvement and other practices at the lower end of Arnstein's ladder (1969). The control of the policy process remains firmly in the Trust and user involvement is limited.

The Strategy does not, however, mention what is a potentially more radical step for the Trust, the involvement of service users in clinical governance including developing and supporting user-led monitoring systems. One service user who had participated in the user led monitoring described the training and initial phases, including gathering information by interviewing other service users and presenting the results at formal meetings. The latter activity he described as *"...like going in to*

see the headmaster..." (Owen), indicating both the level of importance he placed on the involvement and the stress caused by being put into an unfamiliar and formal setting.

Further developments in the Trust took place in 2003 when they published a "public and patient involvement strategy", in which they committed to *"the full participation of users, carers, staff and the voluntary sector in the shaping of its services".* (Somerset Partnership NHS Trust, 2003 p2) The Strategy was developed by a small group including three service user and two carer representatives, two user participation workers and led by the Clinical Governance Manager. There were no clinical representatives on the group. Early in the document, the Trust describe the purpose of their involvement of service users:

> *"Somerset Partnership NHS & Social Care Trust actively promotes the process of Patient & Public Involvement in order to achieve a creative partnership. It is important to acknowledge that it is a process, one which should become an integral strand of the Trust's activities, and not a series of unrelated actions in response to external drivers."* (Somerset Partnership NHS Trust, 2003 p2)

Although stressing once again the vision of a partnership between service users and the services they use, this statement is not otherwise particularly helpful in clarifying the Trust's aims. However, the influence of service users and carers seems to be reflected and this approach might be compatible with the emancipatory aims identified by Heyes (2002). If it is meant to denote a partnership across all areas of the Trust's activity, however it is unlikely to offer a specific challenge to the medical model of care, as service users might hope, because clinicians were not engaged in its development. This is despite the document identifying "professional resistance" as one of three main barriers to user involvement. The two others being "tokenism" and "decisions being made elsewhere" (Somerset Partnership Trust 2003: p.10)

The Strategy also included a three-year Action Plan, which promised significant developments such as training for all staff in user perspectives on mental health, funding for participation and inclusion of patient and public involvement in Board meetings. The minutes of subsequent Board Meetings record participation by at least one service user, predominantly during the standing agenda item: "Public Question Time" (www.somerset.nhs.uk, accessed July, 24 2004). There is also a report of progress on the action plan in the minutes for January 2004. (Somerset Partnership Trust, 2004)

These documents produced by the Trust demonstrate that they recognise the growth of service user involvement as an important issue in mental health services, but there is little evidence from the documents or progress reports to the Board that there is "participation at every level".

The formal policy making body of the Trust is the Board which is made up of Executive Directors appointed by the Trust and Non-Executive Directors appointed by the Secretary of State. Early in the life of the Trust a vacancy arose for a Non-Executive Director. Through the Chief Executive, the Trust encouraged and supported service users to go through the application process. This involved a fairly arduous process of an application to the Regional Office of the NHS Executive and interview, however eventually a former service user was appointed to the Board. A contemporary study by Peck et al (2002) cites her appointment as an important success for user involvement, however despite being mentored by the Chief Executive, her tenure was fairly short-lived and she resigned following a disagreement about the closure of rehabilitation units and conflict over a number of other issues. The danger for the user-member was described by a former user and voluntary sector worker:

> *"...you are in a minority of one, in isolation and not really being loved by anybody because Directors see you as intrusive into their cosy world and service users as*

> *suspicious that you are part of the system, you have become one of them now. So it is a very precarious position for one solitary service user to be in"* (Paul)

Another informant agreed and commented that her position had always been very difficult:

> *"...she was there in her own right, so it was difficult for her because all the users saw her as the user rep, which she wasn't. She applied, she wasn't nominated by them. That being said, she was a strong advocate for the users but it was also trying to deal with some of the difficulties and the tensions of our clinical governance committee. She was a member of it and we brought a thing forward on ECT* (electro-convulsive therapy). *That is a sort of an anathema to many users...it was always going to be difficult for her..."* (Richard)

For others in the service user community, there was an expectation that the appointment of a service user to the Board would change things, but reservations too. Sean thought that she had *"done a lot that is not acknowledged"* for user involvement and that was *"was quite an eye opener for people"* but also that there remained scepticism that *"people who get involved are different"* from other users. This perception was common among both staff and service users themselves.

The individual herself, Diane Brodie was not available for interview but writing in the Speak up Somerset newsletter spoke of an initial confusion of roles:

> *"Who was I? A non-executive director or a service user?...As service users we know we speak a different language to our providers. We talk about issues that affect OUR lives in very real ways...we know what part of the services...have damaged us and what could improve things – but with these views there is no thought of finance or lack of it, government directives...Suddenly as a non-exec I had to balance up a whole new set of issues – and suddenly I felt compromised..."* (Brodie, 2000)

This is the challenge for any service user becoming involved in health service decisions. The profound disagreements based on paradigmatic differences have somehow to be reconciled. Inevitably there is a sense that this is *"sleeping with the enemy"* (Martha), but the dilemma for service users is that if there is no participation, how can things change? And the

further question for users is: if you do become involved, do things change? Did Diane Brodie's tenure on the Board affect the way in which service users are perceived or the understandings of the Trust? It was unfortunate that I was unable to interview Ms Brodie as a more detailed personal perspective; particularly after she had left the Board would have been extremely valuable to the research. However it is possible that there are indications of her effect from other sources. There seems to have been little discussion of user involvement issues in the period immediately after she left and there is some evidence that little had actually changed in the way that the Trust viewed service users.

Service users themselves tend to identify themselves as "survivors" rather than patients, but it is the *latter* term that the Trust used in its strategic document. The use of the term "patient" in the title of the Trust's strategy is justified with reference to its use in government policy documents (Somerset Partnership Trust, 2003). This may be the case in many documents from the Department of Health but not necessarily the case in papers from other government departments. In the body of the strategy, the terms are defined. The document *"...uses the term Patient to refer to people using a NHS service...we have used the term User to denote patient, carer, parent and/or service user.* (Somerset Partnership Trust, 2003: p. 2) So the Trust view is that user is a more general term, which would suggest that the use of the term 'patient' in the title is anomalous in a document that covers the involvement of a wide range of stakeholders, or that it indicates the dominance of a health service approach to delivery of mental health services in the Trust.

Carol, the local service manager, recognised differences in NHS and social services perceptions. She commented that her social services background led to a very different perspective than her manager who had a health background. *"He's a lovely bloke, but forever calls the people who come here 'patients'...he really has less understanding of the social model of care"* (Carol). Similarly, a service user, with a nursing

background told me *"...social workers are far more informed and empathic than your average health worker"* (Sandra).

Peck's study examined the issue of integration of the two perspectives in some detail, concluding that the merger of the two services in the Trust had led to a strengthening of the separate professional cultures, rather than the emergence of a new and shared culture. He found that shared values among the senior managers and members were not reflected by shared views and values among professionals from medical or social services (Peck et al, 2002).

8.2 Service user views of involvement

Most informants agreed that there was a very small group of people who were very important to the service user movement and that they each fulfilled many roles. At a local level, there appears to be more widespread involvement, but most of those service users who took part in group meetings were not interested in participating in decision-making at any other level. Carol, in her work directly with service users had tried to encourage them to speak up *"...but in my experience they don't want to do it"* (Carol). One reason she had identified was a concern that being outspoken about services could affect their treatment and even though they may not be happy about one thing or another, they would not say so in meetings where staff, particularly more senior managers were present.

> At one of the Speak up Somerset meetings, a draft guide to Trust services was discussed at length. My notes record about a third of those present speaking, making very practical suggestions for developing the guide's content and usefulness. When it came to feeding back to the Trust, however, none of those in the meeting was prepared to do so and eventually I was asked to feed back on their behalf. (Observation notes, SuS Meeting July 2001)

One fairly vocal member of this group was Martin who had been involved with services for many years but had never participated in any meetings with Trust managers. Not only was he *"not aware of general policy issues"* (Martin) but he also felt that he would be *"far too biased. It's very time consuming and cost inefficient to get people to join in meetings"*. Unlike others, he was happy to leave the decisions and the monitoring of services to the professionals.

> *"The professionals have personal experience with clients. I regard them as the authority. Professionals are doing the best they can, rather than being monitored by clients they need to do it within their own circle "* (Martin).

Where Martin agreed with other informants was in the common perception of people with mental health problems. He blamed the media for unbalanced *"clichéd and emotive"* coverage.

Another user at the same meeting, James, had recently moved to Somerset. He found it *"more open"* than his previous home, though he also noted that things change only slowly and it was still the case that *"anything to do with mental health has a big stigma to it"* (James). Change was, he thought, evident also in professional attitudes, though there remained a long way to go.

> *"People used to regard doctors and psychiatrists as god-like. Even though the attitude isn't quite like that, the professionals still feel 'we are the professionals, we know'"* (James)

What James advocated was not a radical shift, but mutual respect his view was that service users had something to contribute, something to add to decisions:

> *"...not lessening the respect, but renewing it, limiting it to just their own area of expertise and education. We (i.e. users) are widening our views on things. We want to voice these opinions and not be talked down to anymore."* (James)

James' view is common among those I spoke to, based around civil rights and looking for change, but evolutionary rather than revolutionary change. A third and more radical view came from Walter, a carer who was convinced that there was *"...basically a conspiracy, it's the psychiatrists and the drug companies. They know these drugs don't work, they know they harm people..."* (Walter). Walter may have been at the end of the spectrum of views, but others also talked of the malevolence of service providers. Sandra, for example spoke about the *"small power - small people exercising power...where they can over dependent people"* (Sandra)

These are views that would be rejected by, in particular, health service professionals who believe they are helping individuals. Crawford (2001), for example suggests that psychiatrists and service users share aims and concerns. Summers (2003) on the other hand acknowledges the role that professional power has in maintaining the dominant view, a perspective echoed by Sandra, a former health service professional and survivor who believes that:

> *"what we have now is an entrenched professional interest and it seems to me that medicine is appropriate for the biological. The real concerns of psychiatry are the social and psychological. The biological, medicinal drug interventions are clumsy at best and grossly misinformed at worst"* (Sandra)

Her implication is that the opposite view, that drugs are the preferred intervention remains dominant among professionals. Service user movements may resist the power of psychiatric medicine, but its dominance is reinforced by control of the production of knowledge, the legal framework of mental health and the construction of formal processes for involvement such as the JCB and the Day Services Review either directly or through managers who do not deviate from the assumption that the medical view is most appropriate. These are forms of tokenism that doubly disadvantage service users by forcing them to adopt alien methods

and modes of communication and into tacitly acknowledging the bio-medical paradigm as the theoretical basis for mental health services.

The dilemma for service users is whether they should take part in these forums where their views are neither fully understood, nor valued. If they do, success in terms of the kind of the kind of service change they seek is unlikely. But if they do not, such change is even more unlikely! Brodie quotes Louise Pembrey, a survivor of psychiatric services: *"I feel one of the dangers with collaboration is that we can change the icing on the cake, but we don't change the cake"* (quoted in Brodie, 2000: p. 4).

The Sainsbury Centre for Mental Health, in a report on the user movement in the UK found that there were sharply differing opinions among service users about whether service users should become involved. These were illustrated by the following quotes:

> *'I probably want most of the same things that the most radical service users want, but my approach to getting them may be totally different – sitting round a table with people, not attacking them, trying to work with them and change things from within.'* (Wallcraft 2003: p. 55)
>
> *'What governments like is a nice easy survivor movement to deal with where they have one or two people they know they can be nice to, they can butter up, they can invite to soirées and get on board, and I think that's very bad for the survivors' movement. Survivor involvement is always a dangerous balance between wanting to get access to and influence people without being seduced by the whole process.'*
> (Wallcraft, 2003 p.55)

Clearly the second individual is concerned that the aim of mental health services in involving service users is to incorporate them and reduce the criticism to a manageable level, obscuring the inadequacy of policy (Burton et al, 2004). On the other hand, the opportunities for influencing the agenda of the statutory authorities rely on participating where the agenda is set. One informant, a voluntary sector worker and survivor believed that real change required a different plan of attack: *"power structures today undoubtedly lie with the psychiatrists and the*

government. But government can be persuaded..." (Sandra). The NSF for Mental Health recognises as good practice many of the developments that service users have campaigned for over many years so that through national action, the service user movement nationally has influenced local policy in a way that purely local action could not.

The gulf between the views of service users about services and those of the providers are not in the organisation of services or in the decoration of the premises, they are in the fundamental basis for services, the rights of the service user and the understanding of the appropriate response to mental distress.

A number of informants commented that their involvement had an impact on their own mental health or their recovery from illness. Sean for example put it this way:

> *"In some ways it became a way to fill in my time, it was a kind of therapeutic activity...I did think the sense of community and linking up with people was quite important...(there was) a sense that one was actually trying to do something and recognising user involvement as a way of creating a community of people."* (Sean)

Sandra was also convinced that her recovery and continued health could at least in part be attributed to taking part in the service user movement. Other benefits of involvement included gaining a deeper knowledge of the mental health system, so that in crisis, there were more options available to the service user or their carer. For a number of those I spoke to, their involvement has led to employment in the voluntary sector or the health service.

The therapeutic effects of involvement were balanced by the strain of participation. Roland commented on being unable to relax following participation, while others gave examples of users whose mental health

had suffered as a result of the intensity of their involvement. Paul remembered

> *"...there have been casualties, there have been service users who have been very willing and have participated in a range of meetings, but then they have had to pull away when their mental health has suffered"* (Paul)

Roland had mostly been involved at a local level, but described the effect that taking part in meetings had on him:

> *"I find that I find it fascinating, the complexity but it takes its toll on me. After a complex meeting I find it difficult to chill out. If I did nothing I would be worse off, but the cost is difficult to put my finger on. I get home, my girlfriend wants me to go round, I don't want to see her and its not that I don't want to see her, but the issues are still going on, I am still processing information, my mind Is still working at quite a rate. It is difficult to deal with – or to explain to somebody. Yes, there is a cost but the benefit outweighs it. It is therapeutic but...It is almost like a vaccination, you get a little of the poison and it helps you stay healthy."* (Roland)

Whether user involvement made a real difference to services or commissioning decisions was questioned by several informants. For Sean, it appeared that involvement in the Trust was more public relations than user involvement. He described the part users played in a review of day services, commenced soon after the founding of the Trust was touted as being an example of how the Trust involved users. On a more detailed examination however, service users had little opportunity for real participation in developing proposals or preparing the report:

> *"There was a big stakeholder meeting of about 120 and people put themselves forward for it. It seemed like about half to two-thirds would be service users, but it ended up with a very few in number of service users. I'm not sure whether that was because they couldn't get the service users to be on it. We met about once every couple of months and discussed things and then the report was produced. It seemed like the report...it was the four day-service managers across the localities and (the Trust Chief Executive) who kind of like were involved in putting the report together, it wasn't somebody outside doing that. They did have outside speakers, so there was an attempt to get different views, but the services were kind of like we went to these meetings and then there was a final stakeholders meeting and then the report was produced. I don't think there was much attempt to find out from service users what they thought, apart from the few who were on that group and there wasn't really precisely, I mean I was on it, an ex-service user and somebody from MIND and somebody from Wincanton who was more of*

> *a worker although he had used services elsewhere, but it didn't seem to have a much wider constituency of people involved."* (Sean)

Another perspective was that of Roland who had been a member of a Locality Reference Group for some time and was convinced that at that level there was more to it than an exercise in public relations:

> *"I also sit on the Reference Group...where all the professionals get together its just an information gathering group where everybody puts everybody else in the picture...strategies and what's going to happen...I'm there as...a service user representative there's two of us in members who are designated that. Basically we are there to shout the corner of anybody who is affected by anything that's changing or anything that is there at the moment that needs changing and I think we are there as, I consider my self to be there as perhaps a limiting factor. You know where these people, no disrespect to them but they can't possibly know what its like to be affected by their rules and regulations and how they go about doing what they do. However well intentioned that is, they can't know what it is like to be at the sharp end so accepting that they are reasonable people and they are genuinely there to help us I consider it up to us to inform them as to how it affects us."* (Roland)

Roland clearly feels that his part in the Reference Group adds value and that the professionals accept that the user perspective contributes knowledge and is a full part of a partnership. Perhaps the difference here is that whereas Sean is disappointed, having expected to contribute a specific and rational discourse that would result in a consensus document, Roland's involvement is non-specific, contributing to the on-going management of the service. He views his participation as more political, robustly "shouting the corner" of the service user, engaging in argument, promoting his interest and expecting dispute. Both may appear to be debates in the public sphere in Habermas' terms, but the locality group is closer to the open and accessible space for discourse than the controlled production of policy.

There is a third, more formal process that was raised in interviews. This was one of highest profile examples of user involvement, the participation of user representatives in the Joint Commissioning Board (JCB), the policy making partnership Board for the commissioning of mental health services in Somerset. To begin with, according to several informants, the JCB

meetings were bewildering and confusing for service users who were unused to the protocols or rituals of formal meetings. They tended to combat this by meeting as a group before the beginning of the formal JCB, but this too was unsatisfactory as it meant that meetings lasted a full day and members were exhausted by their participation.

Within the meeting, according to one member, there was a clear hierarchy, with users at the table but not voting members:

> *"...you used to have four County Councillors and four members of the Health Authority and then a chair and they were the only ones of course that had voting rights. We would be looked on more as observers. Although we would be able to put forward our views, they would be listened to and obviously discussed briefly, but the power would reside with the officers who had the direct responsibility"* (Paul)

While the Board was formally charged with making policy, Peck et al (2002) found that its importance was limited and that most decision-making took place at the Joint Executives Team (JET), where key officers met, without the participation of service users. Additionally, Peck found that although user and carer representatives frequently made contributions at the JCB meetings, they rarely contributed items to the agenda or were able to influence decisions.

Many of those who were active in the user movement became willing participants in partnership groups and the JCB when invited. They also found that there were issues that as users they had pushed for were now part of the Trust agenda, including advocacy and twenty-four hour crisis support, which had been part of *"all these new directives coming down from government"* (Paul) however the agenda has not extended to more radical positions such as challenges to psychiatry or ECT, or to the medical model of mental health, so in some sense, the user movement's aims have been moderated by their participation in the group.

8.3 Clinical Views

The Trust Strategy (2003) identified professional resistance as one of the three most important barriers to involvement. Many informants agree that there are some clinical staff who reject the need for involvement, while others support it. A limitation of the case study is the lack of input from psychiatrists who were unavailable for interview. Peck and colleagues study found a similar difficulty in recruiting clinical involvement. Insights into the views of clinicians were offered by service users and managers. Many clinicians supported user involvement but *"...may have a debate about you know the spectrum...the debate would be about the length of travel or the speed of travel, but there would be no argument about the direction of travel"* (Peter).

Other studies (Summers, 2003; Barnes & Wistow, 1994; Anthony & Crawford, 2000) have examined this area and provide useful insights. Professionals are reported to express positive views about user involvement, but what Summers calls dissonance exists between this support and actual practice (Summers, 2003).

In this study, in common with others, service users see professional views as a significant barrier to effective user involvement. Most service users identified psychiatrists as powerful, but less willing to engage with service users. One service user referred to some staff (including clinical and non-clinical staff who resist user involvement as *"the dinosaurs"* (Roland). These are long standing members of staff from all professional groups who began work in the mental health system in large psychiatric hospitals.

> *"They are the people in the service, the staff who joined the mental health profession in the old days when you had the huge hospitals and service users were treated as "nutters", mad people who run down the road stark naked in the morning with an axe. Their purpose was...to keep us out of society in a place of safety...Not for us, for them, for society. I don't believe they ever really interacted with us..."* (Roland)

Roland saw dinosaur-ism as *"institutionalised in the service"* but also identified positive signs as the dinosaurs die out, never the less there were difficulties for the staff with positive attitudes: *"a staff nurse I see as a counsellor...gets flack from the other staff over the way she deals with us".*(Roland) Other studies confirm Peter's view that there is expressed support for the concept of involvement but that it appears to conceal a range of attitudes from optimism to scepticism (Summers, 2003; Peck et al, 2002). Psychiatrists interviewed by Summers adopted a view of user involvement as a means to improve the service provided, taking a scientific utilitarian approach to issues of involvement (Summers, 2003). In contrast, those users and local workers interviewed for this study regarded involvement as part of a process of empowerment with potential for therapeutic benefits for those involved.

8.4 Involvement in Decisions about Rehabilitation Units

Trust support for user involvement was tested by issues that have caused significant tensions. And in the words of a senior manager *"I have been seen as very positive by the users...but I am now the number one hated person"* (Peter). In 2001, the Trust took the decision to reduce the number of rehabilitation places and transfer several small residential rehabilitation units to housing associations. A positive feature of the change being that it would enable users to take advantage of changes to the benefit system. The service changes resulted in the sudden closure of two of the units and the loss of a number of beds *"out of the blue"* (Martha). For the Trust, this was a decision born of both improvements in service through access to transitional housing benefits and income support for users and their own financial crisis. A senior manager reported:

> *"...there's five rehab' units we are talking about and its certainly true of the two that we just closed. We were going to hit up a huge deficit, it was getting out of control and we also had far too many rehab' beds...We had a big financial crisis*

so we closed two (units), I was dead honest about it...but this is the issue of out of the blue...This had to be sorted out by the end of March...it did not allow for long periods of consultation, it had to be pushed and driven through...in retrospect would I do the same thing, yes I would do the same thing, but no I wouldn't do it in the same way. I would have found ways around this and we are not without fault on this for one minute. (Richard)

The problem for service users was that the plans had not been discussed with them in advance of the announcement:

> *"...a lot of people who felt quite angry about that...they had not been told about it...I mean, not everybody was anti it...Some people were saying that it wasn't a bad thing...(it was) mainly that people didn't know about it until it happened. They were also told that one of the justifications was that people wanted these changes, but there was a lot of anger because people were just told that this was happening and there had been no involvement."* (Sean)

Roland was another shocked by the announcement and spoke about how the issue came out and the likely ramifications:

> *"...we were told that it was going to close and basically it was the finances...the ramifications are huge to my mind. My friend would go to Sea View (one of the units for closure) when she felt sketchy, just go there and chill out for a few weeks without going into hospital. So its short-sighted, it will make things worse. Hospital beds are more expensive...it is a cost-cutting exercise and the repercussions will go on for years..."* (Roland)

The consequences for involvement overall might be profound as user involvement in Somerset remains at an early stage, where trust between the service users and the providers is still uncertain with scepticism on both sides.

> *"I still think there are still very few service users who do get involved...I think it is still quite fragile. I think there are still people waiting and watching and thinking well will...we have to step in and go back to a more professionally determined service? I think there are also some service users who are still worried, not wanting to get involved, not least because they see people who do get involved as somehow losing their ability to be critical."* (Sean)

Much of the development agenda, largely nationally determined has been shared by user participants and Trust managers. Unfortunately, the issue of rehabilitation places in the community has led to conflict. The issue is

not the fact of the change, some informants supported the changes, but how the decision was made, without proper involvement or discussion. What one informant called the *"manager's arrogance"* (Peter) may be mostly at fault, but there was an extent to which this was defining what the Trust saw as the "length of travel in that Peter commented that

> *"...it is part of the difficulty that I am in with some of the users at the moment is that consultation doesn't mean agreement or consultation doesn't mean me abrogating my responsibility to manage"* (Peter)

and it is indicative that although it may be unusual not to see service users at meetings, *"...seeing them there and listening to them is two different stories"* (Owen).

Paul's long experience of involvement left him philosophic, yet hopeful:

> *"There are still brick walls to be knocked down, the defensive attitude taken by the partnership, the unwillingness to admit that maybe the whole system needs to be broken down and rebuilt. There are changes, but there is a long, long way to go...you get hardened to disappointment in this business...it ain't going to happen over night, it's a long, hard slog."* (Paul)

8.5 Sleeping with the enemy?

Service user involvement in the Somerset Partnership NHS Trust has brought service users into direct contact with decision-making structures, even for a time to the Trust Board. The development agenda following the mental health NSF (Department of Health, 1999) has encouraged user involvement by bringing issues to the fore that have been part of the user movement's agenda for a very long time. But the process remains fragile and involves only a small number of service users in the County. Arguably, the process of direct involvement institutionalises involvement and mitigates critiques. Service users who take part are forced to alter their approach to change and live within the rules and rituals laid down by statutory agencies. Agendas and minutes, protocols and the access to

resources are all things that have to be learned and serve to protect the status quo and reproduce existing inequalities in power (Atkinson, 1999).

The impetus for users to become involved seems to come in the main as a reaction to personal experience of using services, the belief that services are fundamentally flawed and a desire to change things, to make it better for others and for oneself "the next time". There has been a significant amount of research around user involvement in mental health services. Goodwin et al (1999) report that service users in inpatient settings describe their feelings of powerlessness and loss of control, the feeling that psychiatric hospitals resemble prisons and that treatment feels more like punishment. Lack of information is used by staff as a tool for maintaining control, while users feel that their contribution is ignored. Roland used similar language when referring to his experiences as an inpatient: *"Their purpose was...to keep us out of society, in a place of safety, but who is that a place of safety for? Not for us, for them, for society"* while all service users who had had experience of psychiatric hospitals stressed their feelings of anger and resentment.

Rutter et al (2004) found that for service users, issues of involvement were fundamentally about changing the social status of people with mental health problems rather than making (sometimes superficial) changes to services. Diamond et al (2003) address this issue in their research. They found no evidence that user involvement had been able to challenge the culture of care. My informants tended to see these as two sides of the same coin, but their view of the most necessary change was at the structural level, change to the power relations in mental health and the paradigm of care. I also found that the medical model remained dominant within the Trust, despite the incorporation of social services staff. For managers, the model of care is not an issue, their concerns are achieving policy goals, budget and performance targets. They may be unconcerned that some of the goals set out are in conflict, so long as there are

indications that progress is being made towards them. Some managers, like the Chief Executive, express a personal commitment to user involvement, but the strength of that commitment depends on other priorities, including financial pressures such as those that led to the decisions over the rehabilitation services.

It is important to recognise that the service user movement and user involvement in decision-making are not the same. The existence of a user movement in Somerset pre-dates the Trust and is independent of it. User involvement is one of the activities of the user movement, but there are others like campaigning on a national as well as a local level and mutual support (Wallcraft, 2003). There is debate within the service user movement whether becoming involved with providers is productive. Similar questions were raised by my informants who recognised that their participation was a difficult choice, but a pragmatic one. Participating in practical change in services has to be seen in the context of, and cannot be separated from, a wider purpose which presents a challenge to existing structures. Taking part in the JCB and locality reference groups can be seen as a way in which users attempt to democratise decision-making in mental health.

Once involved, people seem to participate in multiple ways, in formal groups such as the JCB or users and carers group, in working parties like the day services review, in projects such as the user-led monitoring as well as in the user movement through groups like Speak Up Somerset, Survivors Speak Out, Manic Depression Fellowship or MIND. So the growth of participation in the Trust has not been at a cost of reduced user movement activity, but has increased the activity of individual users. Efforts have been made to broaden the base of user participation, but it still relies on a very few people in the County. Although systems exist for in Arnstein's terms, what might on the surface appear to be full participation, the involvement, particularly in formal groups appears very

much on the terms of the Trust and would rarely rise above partial participation as formalised meetings with minutes, a chair, an agenda and papers will exclude many users who are unfamiliar with these processes or unable to attend regularly. Similarly, in the day services review, the impression that there was a significant user and carer participation appears to be an exaggeration. Not only was there less of a representation actually at the meetings, but there was also a lack of input into the report, which was authored by the day services managers.

For service users in mental health services, there are costs and benefits to involvement. Several informants thought the activity therapeutic, providing an interesting activity and in one or two cases employment. On the cost side, users refer to the strain of long, formal meetings, difficulty in chilling out following meetings and longer term consequences for some individuals.

The role of clinicians in user involvement in Somerset mental health services has been minimal. Their support appears to be variable and there are some who, according to both managers and service users are hostile. According to other research, mental health clinicians see the participant users as unlike "their" patients and question their representativeness in a statistical sense. Summers found an assumption among psychiatrists that representation should be interpreted in purely statistical, rather than democratic terms (Summers, 2002).

Psychiatrists are not alone in this view. A similar assumption was present among clinicians from cancer services in the same area. Their overwhelming assumption was that service users would be involved through some indirect process such as questionnaires or, as in Taunton, focus groups (Tritter et al, 2003). Their input would then be mediated and summarised by professionals who would bring it to decision-makers.

Staff views of user involvement were found to be mixed in Rutter's (2004) study of user involvement in London although in Diamond et al's (2002) study, in Nottingham, staff acknowledged the importance of user involvement. In London, mental health nursing staff saw user involvement as misplaced political correctness which added to their work, but which they were not prepared or trained for (Rutter et al, 2004). The consequence of lack of clinician involvement is that clinical issues are largely untouched by user involvement at a local level. They may be raised by service users, but managers have to take them to clinical colleagues separately, but do so without the personal commitment shown by users. However as change has happened at national level, the need for local translation of national policy has meant that some user aims have been achieved.

In Somerset there was also a mixed view among staff according to both managers and service users. Those managers interviewed expressed strong support for user involvement at both local and County level. Managers saw involvement as supporting some managerial functions, achieving policy objectives and helping to justify their decisions. However there were also problems in getting sufficient users involved and there was an issue of their ultimate responsibility to manage. The Chief Executive expressed strong support for user involvement and was instrumental in getting a service user on the Board and supporting her while there. However the credibility that this gained with service users was shaken by the largely symbolic place of service users in the review of day services and largely lost by the Trust's failure to ensure that service users were involved in decisions about the future of rehabilitation services. Whether there was general support among colleagues or fellow Board members is also questionable. There are few items relating directly to user involvement in any Board meetings and documents like the Trust's Clinical Governance Strategy (Somerset NHS Trust, 2003) and even the Patient Involvement Strategy (Somerset Partnership NHS Trust, 2004) appear to

be developed in isolation from involvement practices such as user-led monitoring or locally based participation in decisions.

Unlike cancer services, where the purpose of user involvement is identified as improving the quality of care (Avon Somerset and Wiltshire Cancer Services, 2001), Somerset Partnership did not identify a clear objective for user involvement, even in their Patient Involvement Strategy; however service users themselves clearly linked their initial reasons for becoming involved to change not in services but a transformation in the model of care and attitudes of the public and providers of care. As Barnes (1999) found, many users identify themselves as mental health survivors, a social movement that aims primarily to transform the mental health system and ultimately society.

A number of leading members of the Speak up Somerset group declined to participate in the research and at the meeting expressed scepticism about participation in health service decisions, preferring to remain outside of the process. This emphasises that the service user movement is independent of and to an extent remains unconvinced that the health service decision-making process is open to their participation. It may be that there are different levels of openness at levels of policy making. One informant spoke about the influence that user groups could have on national policy, maintaining that although involvement in local policy making was an important step, it was at a national level that the effect was greater. For others, including Roland and Carol, very local decisions appear more open, however important decisions are made at the level between these two. It is at this level, where Trust policy is made and at which the JCB operates that there appears to be less openness and involvement. There was initially a good deal of positive feeling generated among service users by the Trust's development of new services. Advocacy services, assertive outreach and 24 hour crisis care had been aspirations of service users for a very long time. While they may have

more to do with the National Service Framework for Mental Health Services (Department of Health 1999) than user involvement in decision-making, the result was that the Trust appeared to be listening to the voices of service users.

Peck's (2002) evaluation of the merger in Somerset found that within the County there was a well-networked governing elite that ensured that tensions between health and social services that might exist elsewhere were minimised. His analysis of user involvement in Somerset suggests that despite rhetorical support from management, participation at Board level and symbolic inclusion across a range of organisations, service users still do not have access to decision-making structures. My research concurs with most of these findings, particularly when the example of the rehabilitation beds was discussed however I also found that at a local level there was evidence of user led agendas in day centres and in locality reference groups, with staff supporting user interpretations of events.

An interesting aspect of this study is that the Partnership Trust brings together staff from social services and the NHS in a single organisation. The integration was not without its problems and Carol's view of the tensions inherent in the integration is mentioned also by Peter, who concludes that it has worked through well. However Sandra's comments tend to contradict that. Her view, shared by Beresford (1998), is that the important factor is the training and socialisation that professionals go through and that social care staff will always have more sympathy for the social model of health than health professionals.

8.6 Summary

The direct involvement of service users appears to be the preferred approach among managers and service users in mental health. This is in contrast to the assumed approach suggested by clinicians and the most

prevalent approach found in the survey of health authorities. In Somerset, involvement in the JCB, the Trust Board, in locality reference groups and in user-led monitoring brought service users directly into contact with (apparent) decision-making bodies. The real status of groups like the JCB was (according to Peck et al 2002) more as the symbolic partnership forum rather than the place where decisions were actually taken, however the presence of service users in these forums raises their status and provides access to the "governing elite" and ensured that their concerns were aired, even if decisions had been taken in the closed Joint Executive Team by senior managers.

Chapter 9: Power, resistance and partnership

9.0 Introduction

In this final chapter, I will draw together the results of the case studies and survey and consider them in the context of the theoretical and policy perspectives discussed in Chapters 2 and 3. However firstly, I will discuss some other issues and difficulties encountered in undertaking the research.

9.1 Issues with the research

This research has been conducted over a comparatively long period in what has been a rapidly changing field. There have been both positive and negative consequences from the length of time taken to complete the project. First of all, my professional involvement in the field stretches back to the late 1980s and I have observed and been part of the development of the involvement of citizens and service users throughout the period under study. This has given me insights that someone involved for only a short time would not have such as an understanding of the pace of development and some of the shifts in the language and practice of involvement and the impact of major policy change.

The research itself began in the midst of perhaps the most profound change, the election of the Blair administration in 1997. Since beginning the research in 1998, public services have been through massive change. The New Labour project of modernisation is summarised by Barnes et al (2004) as democratic renewal, performance improvement and capacity building. In all three, the public have a role as service users or citizens. Modernisation has resulted in the abolition of health authorities, the creation of new primary care organisations and "strategic" health authorities and the development of national agencies for quality assurance

and assessment of treatments. These policy shifts caused significant change in the detail of the research, including the settings for the case studies, however the underlying theme of assessing the involvement of the public in health service decisions remained constant. The growth of an agenda that seeks to mobilise public services to address long standing and intractable issues that cut across departmental remits has introduced new stakeholders to the health policy community.

NHS organisations now have a "duty to involve and consult" local people (Department of Health, 2001). Community Health Councils, once accepted as the "patient's voice" have been abolished and new structures are now being constructed to develop service user and public involvement in health service decisions. Lay members on Primary Care Groups (PCGs), like the PCGs themselves have come and gone, but "patients' forums", once formed will have rights to board membership in all NHS organisations (Department of Health, 2002). Local authorities will also have a role in the scrutiny of local health services and service planning (Department of Health, 2002). This research does not attempt to assess the impact of these new structures and it is perhaps too early to do so, but the conclusions from this research may provide insights into the likely success of the new processes.

A significant weakness in the research has been the lack of involvement of clinicians. Only three interviewees were medically qualified and while others did participate in some of the meetings observed, and many other interviewees expressed their own opinion of what doctors believed, it was not possible to investigate their views and attitudes in any depth. It has been possible to draw on other researchers' work to partially close this gap, but the importance of clinical views in the decision-making process means that there remain questions over the relative influence of Alford's "dominant" interest. The importance of medical perspectives in defining health and illness and in establishing a framework within which decision-

making takes place should not be underestimated. Although in Alford's model, the corporate rationalisers, usually viewed in the health service in the UK as the managers, have gained influence through successive reorganisations, (Alford, 1970; North, 1997) the framework for decision-making has remained medically led. The absence of the doctors' perspective specific to this research means that an exploration of the compatibility of health service decision-making and public participation in decisions can not be comprehensive.

9.2 The contribution of the survey of health authorities

Coming, as it did, at the very beginning of the Blair government, the survey of health authorities provides an indication of the progress that had been made in the development of public involvement in the health service to that point. Its findings that any progress had made little impact on the planning of health services, but had led to some promulgation of policy probably shows that the national initiatives from "Local Voices" through to "Patient Partnership" had been regarded locally as *"boxes to tick"* in the words of North Bristol Trust's Chief Executive, rather than areas where that required changes in management practice. Later surveys (Rowe & Shepherd, 2002; Florin & Anderson, 2002) found very much the same picture in primary care groups. These showed that public involvement was one of many priorities for managers in the primary care groups. Policy directives in this area were not accompanied by targets or performance assessment, which turned all but the committed away from the development of robust processes of involvement at local level. So although many health authorities had structures in place and had experimented with a range of approaches, almost half did not budget for the activity and among those that did, most were spending under £25,000. In contrast, flawed initiatives like the Patient's Charter were strongly centrally driven, well resourced and backed by performance assessment targets.

9.3 A Question of Trust

Speaking at the Speak up Somerset AGM in 2002, the Chief Executive of the Somerset Partnership Trust told the group *"...ten years ago it was unusual to see a service user at a meeting; today it is unusual not to!"* (Observation notes, March 2002). As this suggests, the growth of service user and public involvement in what can broadly be called planning and decision-making processes has been dramatic in the ten years since the publication of Local Voices (NHSME, 1992). But when asked about this phrase, service users tended to be quick to respond as Owen, an informant from the mental health case study did, *"...its one thing to see them there, quite another to listen to what they say..."*. In case studies of the involvement of citizens there was a similar scepticism about the whether their participation would have any impact on decision-making. The survey found that in 1998 while there was much activity and close to half of health authorities had incorporated public involvement into their management through development of structures and policies for involvement as part of their planning process, there were few examples of change in policy that could be attributed to that involvement.

Even where there were more successful developments, such as in Knowle West, the trust built up between the "band of brothers" and local people in the first phase of development quickly evaporated under the pressure of the dispute over the reception area. In the North Bristol Trust also, people questioned the competence and motivations of health service planners as well as their real willingness to change their initial view of the best way forward.

Gilson (2002) notes that trust is a psychological state that exists between actors and involves a degree of risk about the uncertainty of motivations and behaviours on both sides. It can be seen as rationally based on

calculation, but is more likely to be rooted in emotions, allegiances and expectations.

The issue of trust in government and public authorities is one that has been discussed by authors from around the world (Harris et al, 2004; Maenda & Miyahara, 2003; Ulbig, 2002). In general, in democracies it appears that there is scepticism about decision-makers. There is also evidence of an active rejection and mistrust of decision-making in the public sector. Public sector agencies are assumed not to be open organisations and to have hidden agendas that do not match those of local people. The origins of the mistrust of public officials appear to be in the demonstrable incompetence of previous decisions. Some public sector workers achieve more trusted status by demonstrating a commitment to the goals and needs of local people. This may be through their boundary-spanning activities or close working relationships. The perception of local people is that these people are not "the council" or "the health authority" but are linked closely with the local community. In user involvement, the existence of boundary spanners in the same way does not seem to be evident. While there is support for public and user involvement among managers, it appears to be more in terms of a theoretical support rather than the active support evident in boundary spanning. There are exceptions and it appears that there is a group of managers who share a commitment to involvement equal to that of boundary spanners.

A survey by MORI for the Audit Commission (2003) on trust in public institutions found that public managers were not highly rated against important indicators of trust such as honesty, competence and communication skills. In contrast, doctors persistently score highest (and politicians lowest) in surveys of trust in professionals (MORI, 2004). Heenan (2003) found that voluntary organisations were more trusted than public sector agencies to deliver services by people with disabilities, while the voluntary sector in general finds trusting government difficult (Harris et

al, 2004). A Japanese study identified a number of factors that were related to trust, including openness, concern and shared values (Maenda & Miyahara, 2003). Similar conclusions are forthcoming from Ulbig's (2002) work in the USA, where he highlights that it is not only the outcomes of decision-making that contribute to trust but the process of decision-making itself. Openness, a voice in the decision and perceptions of neutrality are important here. In regeneration based on partnership working, research has found that where decisions appear to be made in private or where communities are suspicious of motives, there are serious problems of mistrust by the community of public agencies (McWilliams, 2004).

These results appear familiar in the context of the three case studies. The closure of the rehabilitation centres in Somerset is a case in point, where it is the way in which the decision is made, rather than the decision itself, that stimulates resistance from service users. In Knowle West, the sharing of values between the band of brothers and local people at the beginning of the project has a long lasting effect on the process and the breakdown of trust over the reception desk relates partly to the outbursts from staff that were offensive to local people and could be seen as a manifestation that shared values or common ground were missing. This clearly indicates that mistrust is not all one way but applies equally to the health service's trust of those it seeks to involve.

9.4 The Contemporary Practice of Public Involvement

Approaches to involvement varied considerably in the approach used, however the survey, and subsequent surveys (Rowe & Shepherd, 2002; Florin and Anderson, 2002) suggest that the case studies include more direct involvement of service users than was common. Direct involvement brings service users and members of the public directly into the decision-making groups as members of groups or processes where decisions are

taken. Indirect involvement on the other hand offers participants opportunities to express their views on issues in forums that may be reported to, but are not part of decision-making bodies.

In Somerset, for example, the Health Authority had developed a considerable reputation for public involvement in the 1990s, largely as a result of the innovative approach adopted in the early nineties, when "health panels" were developed using a focus group format to discuss health priority issues (Bowie et al, 1994). This, indirect approach to involvement offered a sample of local citizens opportunities to discuss issues of importance to the health authority in some depth, however although it might provide some input into internal discussions, it was not necessarily linked to a particular decision or policy.

There is not always such a tenuous link between the questions asked of focus groups and the decisions taken however. In North Bristol, both focus groups and self-completion questionnaires were used as methods of gathering public views of their development proposals. Focus groups, which I ran, were designed to gather views about specific questions posed by the programme board, including which of the four options offered was preferred. Participants' views were quite clear and were reported to the programme board at subsequent meetings. Their reaction was to alter their approach to involvement, attempting to promote their perspective rather than reconsider the proposals.

Where involvement is indirect, even where the results are so clear, or there has been a comprehensive process of discussion as in the citizen's juries run by the Kings Fund (Sang, 1999) the "authentic" voice of the public or service users is mediated by service managers and/or researchers. This can both translate comments into "acceptable" language and dilute the strength of feeling of individual service users (Barnes & Bowl, 2000). In Somerset, the Health Authority's Panel

approach was adapted, for use with users of cancer services in the Taunton and Somerset NHS Trust. Service users were invited to discuss "site specific" issues in a focus group format. Their input was mediated by a GP who presented summaries of discussions to the cancer teams as part of their clinical governance work. The response from staff was often defensive and in some cases criticisms were rejected as inappropriate or uninformed (Tritter et al, 2003). There was, as in North Bristol, no commitment to act on the comments or respond to them. Nor was there a process for feeding back the reaction of the clinical teams to the participants. User involvement was, in these cases, marginal to decision-making and may even have hindered change.

These examples imply a desire on the part of health services to retain control over local decision-making, despite pressure from both central government and local populations. The purpose of this activity, one North Bristol Trust manager called *"drawing fire"* (Steven), rather than contributing to debate. Indirect forms of involvement on their own seem rarely to extend much beyond information gathering and rarely reach even partial participation in Arnstein's (1969) terms.

In Knowle West, the majority of those involved in any way took part in events staged at the Health Park, including "health fairs". Views and opinions were gathered in often innovative ways such as through "vox pop" recording and video booths as well as through questionnaires. Once collected, their views were analysed and reported to the decision-making groups, just as in Somerset and North Bristol. The difference in Knowle West was that some local people were *also* involved directly in decision-making groups. The local presence on these groups meant that there was a voice to promote or explain local views as expressed in larger meetings.

Decisions about the form and process for public involvement were taken exclusively by the service planners and managers in all these cases and

only in Knowle West was there any further input from citizens or service users. The preference among service managers for indirect involvement can be seen as a reflection of the dominant culture in the health service. Other forms of evidence used in decision-making, it can be argued are the outputs from positivist research which minimises the importance of the wider context for involvement. This is precisely what the public views added to the process in North Bristol, but it was largely disregarded by the Programme Board as they focused on changing minds.

In Knowle West, both strategists and local people recognised the importance of the nature of the area for the Health Park. In the early phase, the "band of brothers" were willing to adapt their "normal" approach to planning to accommodate local people and enable them to participate fully. Problems emerged later when there was much less flexibility in decisions about the reception area, but in the latest phase, there are some signs that those local people who have gained experience of taking part in meetings are challenging conventional approaches to decision-making in the health service. The role of community development workers and other boundary spanners in encouraging and supporting people though these processes should not be underestimated. Informants from the local community confirm that their support has been crucial in the later stages of the development.

In Somerset, the differences in the interpretation of mental distress between service users and the Trust have meant that in order for user involvement to take place, one or the other has had to accept that their view is not dominant. Service users have usually been the ones who have chosen to participate on these terms and it has compromised their ability to bring about change on the scale that they believe is necessary.

One of the issues raised consistently in the research was the extent to which the views of those participating was "representative". This term was

used variously to cover two very different ideas. On the one hand, the statistical concept of representation was raised by both clinicians and managers. This use of the term assumes that demographic similarities, including age, gender, condition and socio-economic status are related to similarities in view or perspective and that participants unlike the overall population in those terms are unable to present an unbiased view. On the other hand, the idea of representation as a democratic concept implies speaking for a constituency, representing their views and having accountability to them. So mental health service users participating in locality reference groups may be representative in democratic terms, however their views may be disregarded by managers on the grounds that they are not seen as representative of the client population in statistical terms.

Indirect involvement also enables managers to exert full control over the form of involvement. They are also in a position to shape the output, both through their control over form and because of their role in mediating the response. Finally, their control over form and mediation enables them to manage the extent to which the output is used in the decision-making process. Harrison & Mort (1998) conclude along similar lines that health service managers use involvement to support their position or, marginalise it by reference to issues of representation

In mental health services there had been considerable efforts to involve service users in the commissioning of services through their direct involvement in decision-making bodies, while in the Knowle West Health Park, local people were directly involved in a range of decision-making groups including the high level policy group. The Somerset Partnership developed structures that placed service users at all levels in their decision-making, including actively promoting their involvement at Board level, with support through locally based user participation workers and mentoring from the chief executive. Evidence of impact on decision-

making was difficult to find in the mental health service, although the coincidence of the user and Trust agenda led to the development of a number of services that met the aspirations of service users in Somerset.

In their decisions over rehabilitation places, the failure to involve service user representatives was admitted as an error of judgement by managers (called by one informant "managerial arrogance"), while the depth of their commitment to involvement could be indicated by both the resignation of the service user appointed to the Board and their failure to involve service users in the rehabilitation decision. There is also a sense in which the attitude to user involvement in the JCB was also a failure of commitment to user involvement. Users felt so concerned about their ability to effectively take part that they decided to get together and meet before the main meeting to discuss the agenda and plan their participation. Little allowance appears to have been made by the "traditional" members of the JCB to accommodate the needs of service users, Peck et al's (2002) conclusion that the JCB was stage managed confirms that within Somerset, the real decision-making structures continued to exclude service users.

For service user representatives, the issue of rehabilitation services led to a significant loss of trust, which was exposed both at the Speak up Somerset AGM and expressed by informants in interviews. It was a reminder for the Trust that user involvement, while apparently well established, remained fragile. It appeared strongest at local level, where managers had developed close cooperation with their clients in local decision-making.

9.5 Perspectives on the Purpose of Public Involvement

The increasing incidence of pubic and service user involvement in decision-making processes, together with the apparent lack of widespread impact begs the question of why health authorities, NHS Trusts and primary care organisations have adopted the approach, and what it is that service users and the public get from their participation. Was the work prompted by the government policy guidance (Department of Health, 1999;2000), local factors within the health service including the personal beliefs of NHS managers, prevailing perspectives on public sector management and the autonomous growth of interest and identity groups focusing on health issues? Or was it seen as the result of pressure from activists in service user movements, health service pressure groups or the community health council for input into service planning?

Rowe and Shepherd (2001) in work related to this study identify three purposes for public involvement in the health authorities' successor organisations, Primary Care Groups (PCG). Involvement was seen variously by PCG board members as fulfilling the need for local accountability, as an approach to improving the quality of services or as a way of improving health through a process of empowerment of communities.

We can see a similar picture in the case studies, with managers recognising the potential role for service users and the public in legitimising their own decisions, contributing to the clinical governance or quality agenda and providing a vehicle through which people may be empowered to improve their health. The expressed support of managers has previously been found to be limited to the theoretical. Their support was balanced by criticism in equal measure .

In their study of cancer services, Tritter et al (2003) found that a consensus statement on user involvement aligned the process to the quality improvement agenda. This finding has similarities to those of Rowe and Shepherd (2001) who found that all perspectives agreed that involvement would improve service quality, though for some this was only one of a number of objectives. As Tritter and colleagues (2003) report, there was considerable disagreement among some participants in the development of the consensus statement on involvement in cancer services, particularly those who were from the voluntary sector about the ranking of purposes for involving service users and although they may be able to buy-in to quality as an objective, it was not highest among their priorities. Quality improvement can be seen as more or less politically neutral and although at deeper levels, there may be arguments about what represents improving quality, the generalised aim of better services is uncontested. Where the political issue of empowerment or challenges to existing power relations and definitions of benefit enters the discussion agreement is more problematic as Skelcher (1993) suggests.

In mental health, there were also differing perspectives over the purpose of involvement. Service users were clear that in the long term their involvement was as a means for them to challenge the mental health system and to promote the social model of mental health. For managers, it was a way to ensure that the Trust were able to comply with the view of quality laid down by the National Service Framework (Department of Health, 1999). Some local managers from the Somerset Partnership Trust might be sympathetic to empowerment in the long term, but for the senior managers, involvement of service users was an important feature of the new organisation and indicative of an open and inclusive organisation, occupying a symbolic, rather than a practical purpose. While service users were welcomed into the JCB, for decision-making purposes, that body was reduced to a discussion forum and decisions remained the province of the governing elite. Managers recognised limits to

involvement, though these were not necessarily explicit. Ultimately, decisions were theirs to make and user involvement was only one part of the process of making them.

For the health service managers and those from other agencies who initially worked with local people on the development of the Knowle West Health Park the purpose of involvement was to transform the delivery of health services to the people of the estate. The "band of brothers" radical vision was a new way to plan health services, which put the views of the service user at the centre. From the point of view of local people, their aims were to improve access to health services within the local community and to ensure that the services that were provided met local needs. The Knowle West community were generally mistrustful of statutory organisations as a result of a long history of disappointments but at the early "band of brothers" stage of development, those involved from the statutory services demonstrated their commitment to developing a partnership with local people. Their involvement ensured local accountability, which was seen by those involved as a critical part of the process of developing the health park. Important in retaining the trust of local people were workers from the health service, the local authority and the voluntary sector who were able to work closely with the local community and work with health service and local authority manager.

For the health service organisations involved, as opposed to the individuals, the involvement of local people in health park was essential to develop health facilities in one of the least healthy communities in Bristol through the mechanism of a partnership involving the local authority that gave access to additional funding sources.

From the North Bristol Trust viewpoint, putting the Trust view forward was, in the words of their head of communication, *"the whole point"* of the public involvement effort that led to more than 2,000 people taking part in

meetings or commenting on plans. Initially however, the Trust may have taken a slightly different position, introducing local involvement in their planning process to fulfil the needs of the Department of Health's process. However their view changed when they found that local people not only opposed their plans, but introduced issues that had not been considered by the Trust such as the environment and local employment. However they had to defend their plans as they were already at too advanced a stage for significant change.

The reaction of the Trust to the contributions of local citizens was not to reconsider their plans, but to re-double their efforts to get the public on their side by making their points even more strongly. This strategy was probably the result of the Trust's scepticism about the ability of local people to make a valuable contribution to their planning.

Those who took part were prompted to do so primarily by their feeling that the Trust's plans were flawed and that the result would be a loss of access to health services in the local area. Those who participated in the focus groups reported that they wanted to make their point, despite not believing that it would carry much weight in the Trust. They believed that decisions were too far advanced to be changed but still wished to have their views recorded.

Local Accountability

New public management and third way policies have embedded new approaches and introduced new actors into the functioning of the state. Partnership working requires a different approach to accountability. Accountability processes have become increasingly complex in multi-agency working and multi-organisational services. As several managers who were involved found, there could be conflicts between their organisation and the partnership. Managers could be unsure whether

their authority extended to committing their organisation to work that was focused on partnership objectives. Acting in this environment could mean taking risks, which could result in personal consequences.

Boundary spanners were particularly at risk in this situation. They tended to see their accountability as to local people, relying also on their own management's understanding of the nature of partnership to ensure acceptance in their own organisations. This was more likely in the local authority, where many boundary spanners were employed as professional community development workers, expected to work closely and cooperatively with local citizens, less so among health service managers who were expected to adhere to organisational priorities. So we see the reaction of Karen's Director to her involving other agencies in "our business", and Carol having her "wrist slapped" for circumventing the usual process in support of local users.

More traditional organisations may not understand that 'many hands' are now involved in governance (Sullivan, 2002), but that this can conflict with performance measurement based on departmentalist models (Mulgan, 2000). The New Labour project of modernisation appears to incorporate both performance management agenda which seeks to control through measurable change and the democratisation of public services in an unresolved conflict so that joining up of local effort is recognised as vital to securing local well-being, but there are no performance indicators for trust and health services still have to meet performance targets for waiting lists.

Just how this can affect decision-making is illustrated by the health action group. The HAG was dramatically different when local people attended, it became an agenda setting group and local people were able to lead the development of the agenda, putting their concern for drug treatment issues at the top and reducing the importance of smoking and diet. When

they were not there, the group tended to focus only on the detail of implementing the agenda and accepted the priorities.

9.6 Power, Resistance and Partnership

Power, resistance and partnership are related concepts which play a major role in the practice of public involvement in health decision-making in the contemporary health service. We can regard power as both the potential to secure outcomes and employing technologies to do so, an approach that acknowledges both structural and active understandings. In the health service, the traditional dominance of medicine in policy debates (Alford, 1970; North & Peckham, 2001) has, arguably, been challenged in the last two decades by the empowerment of management (North, 1995), but in recent years, government policy has also promoted the interest of the community (Department of Health, 2000; Coulter, 1999). Resistance, related by Foucault (1994) to the exercise of power, provides a counter-balance and emphasises the importance of struggle (or agonism (Mouffe, 1996)) in public discourse as part of a process through which decision-making can be legitimised. Partnership can be seen as offering a model through which the participation of the public and service users can be institutionalised in public services. However obstacles remain to the realisation of this model, some of which are highlighted in the case studies.

Power, resistance and public involvement

The exercise of power is evident in a number of ways. Health organisations, while offering participation, control the form, content and rules of participation events and may also have the ability to manage or mediate the output from participation. Even when involvement is direct, the ability to control the agenda and format of formal meetings means that participants may be marginalised. So health managers could both comply

with and resist the policy of involvement that did not fit with their view of priorities.

Citizens and service users may be able to adopt strategies to resist this form of control; some, as in Knowle West may be sufficiently assertive and knowledgeable to challenge the control of health services. This was the case in the health action group, where local participants were highly influential; partly this was because they had gained experience and gone through a process of personal development in previous phases of the health park development; it was also assisted by the level of commitment to involvement on the part of some health and local authority managers; the third factor was the presence of community professionals who were trusted locally and able to facilitate the involvement of local citizens by acting as boundary spanners. In Somerset and in North Bristol there was a notable absence of advocates for public or service user views in decision-making forums, although at a local level in Somerset, managers seem to take on this role.

Those who were most active in Knowle West referred to how the process of formal meetings had the effect of turning people off becoming involved in groups discussing the development of the health park. In the other case studies, the same issue arose in different forms. In mental health, speaking at the JCB was seen by at least one user as like going before the headmaster, while others were tired or stressed by the length and formality of the meetings. In North Bristol, meetings were strictly controlled by the Trust by their setting the venue, format and agenda. Hughes (2003) notes that within formal meetings, discourse is structured, bounded, ritualised and asymmetrical, with some members privileged. The agenda serves to structure the meeting, drawing the discursive boundaries and controlling the order in which issues are discussed. The chair on the other hand may exert control over the opportunities that individuals have for speaking. In formal meetings like the JCB, this can

serve to offer the opportunities for service users to give their views, or may serve to limit their opportunities. The 'stage management' of the JCB in Somerset was referred to by service users and was highlighted in Peck et al's study (2002). Although this amounts to manipulation by the statutory sector, it does not mean that the views of service users may not still have been influential in decision-making, simply that their involvement was indirect.

When people persevered with their involvement, they could eventually be enabled to have an impact despite the structure of the formal meeting. Where the structures of power tend to be weaker is when participants take opportunities to challenge them on a micro-political level. This may happen when partnerships bring together powerful interests who are wary of each other. Maggie's description of how her participation was instrumental in progress for the Health Park is especially indicative of how apparently weak partners can influence progress. The opportunity for local people to be involved creates spaces for resistance to the medico-managerial model. The rules of participation are a barrier only to the extent that participants observe them, by not knowing or taking no notice of the "rules" in the Health Action Group, Knowle West residents were able to impose their priorities.

The notion of power and resistance as positive, active and pervasive forces comes from Foucault (1994) among others and it is in the meetings that once acclimatised, participants can exercise power. There are, as we have seen, alternative discourses of health that come from mental health, communities and alternative practitioners so that although the power of the health system is impressive, it does not represent a fixed and stable position. Even within the health service, health promoters and public health professionals dissent from the conventionally accepted medical model of health. Foucault's notions of power and resistance are helpful in understanding how public involvement can influence policy making.

Power and resistance are seen as being interrelated is important to understanding public involvement in the context of patently asymmetrical power relations. The discourses of resistance run counter to those of power and are in opposition to them, but as Mouffe suggests, argument and dissent are necessary for the practice of democracy (MacLeod & Durrheim, 2002). Kulynych (1997) similarly identifies participation with both resistance and deliberation and it may be that in seeking to revitalise democracy, the government is reawakening dissent. At the micro-political level, particularly where agency representatives are sympathetic, local people demonstrate the ability to shape agendas and to determine the direction of services in the face of professional opposition. It is possible that in Knowle West this process has advanced a stage further in that the actions of local participants have made inroads into the structural barriers to participation in decision-making (Giddens, 1992). The evidence for this comes both from the Health Action Group and from those involved in the Park, who seemed to view the Health Park as a less radical, more controlled development than their own.

Professional power

Professional involvement in all case studies was minimal. This is a reflection of the part that professionals have taken in the practice of public involvement in recent times. While those clinicians who were interviewed expressed a level of support, it tended to be assumed that the process of public involvement was a form of research rather than democratic practice. Tony, a GP in Knowle West saw everything behind reception as inappropriate for local involvement, while the NBT view that the "model of care" was for the consultants to design and was not part of the involvement work (nor were they). These views clearly delineate the boundaries for public involvement for those clinicians involved and in part illustrate the dissonance found by Summers in her research with psychiatrists. GPs in Knowle West were not engaged with the community

or with the involvement strategy and attended the Health Action Group only rarely. Tritter et al's (2003) study of user involvement in Cancer services, revealed a broadly similar picture among professionals in cancer services. Their attitudes, like those found by Summers (2003) in mental health services were at best lukewarm, at worst actively hostile and focused purely on indirect involvement based around research techniques.

Professional power is Lukesian, third-dimension power deriving from the mystique of the knowledge base of the medical profession and the institutionalisation of professional control over definitions of health and illness. Professionals are able to exercise power in absentia. As Sandra, the Healthy Living Centre Manager said, all developments have to be screened to assess the likely reaction of GPs. However the co-existence of power and resistance raises a question as to whether the lack of participation of doctors in programmes of public involvement might represent resistance to the power of the government to impose new agendas on the profession. In general, the role of doctors in policy and their relationship to public involvement is one that deserves further research. Indeed, my research casts doubt on previous work that suggests that managers are a challenging interest in the health service. I suggest that the dominance of medicine in the health service is not, as Alford and his followers suggest challenged by the rise of managerial power (Alford, 1970, North & Peckham, 2001). While managers may have become empowered, it is not through annexation of professional areas of dominance. Managers concerns are likely to be efficiency and cost containment, and rely on the professional clinical role and on professional knowledge in negotiations. As Griffiths and Hughes (2000) found, managers adopt clinical modes of rationality and they may also readily accept professional definitions of knowledge when working with service user or public groups. Unlike Alford's characterisation as a "challenging interest", managerial power may be complementary to professional power. While professionals exert control over concepts of health, managers are

more concerned with controlling how decisions are implemented ensuring the health of their organisation by responding to the targets imposed by central authorities.

Exactly what the influence of the new players in the health field, like local authorities, the Treasury and the New Opportunities Fund will be in the long term is another area that deserves more detailed research. At present, they appear to accept the medical model less readily. Like activists in social movements, they are not as influenced by medical explanations of health as are the health service managers.

Public involvement and the Partnership Agenda

Since the election of new Labour, 1997 market-led solutions have been superseded by third way approaches in which rather than mimic private sector approaches to allocation, public services are delivered through cooperation between agencies. The Conservative approach was initially underpinned by the belief that market-like structures could successfully provide public services responsive to the needs of the public. In the view of at least one Secretary of State, they were supposed to be more effective as a means of accountability than democratic processes (Waldegrave, 1993). However the faith in the ability of the market to deliver health services gradually waned in the 1990s. For critics like Giddens (1997) neither unresponsive hierarchies, nor competitive or quasi-competitive systems have provided solutions to the intractable problems of public services (Rowe & DeVanney, 2003).

There is a tension between departmentalism and addressing cross-cutting policy themes like social exclusion through partnership working (Foley & Martin, 2000). Stewart (2002) identifies the key organisational obstacles as the inflexibility in public expenditure and rigid departmental boundaries. Budget control and performance management are incompatible with

blurred boundaries between organisations. However, increasingly other agencies, including the National Lottery, the Treasury, The Office of the Deputy Prime Minister and local government have taken an interest, funded and developed partnerships with health service organisations. This had meant that the traditional medically dominated health policy community has been opened to other statutory bodies who, like NOF focus on policy themes such as social exclusion or economic regeneration and are "tough on the causes". This contrasts with the more traditional model of providing well bounded and defined services. The effect of these new agencies is to alter the prioritisation of health related developments from health service to loosely defined health improvement.

Third way policies seek to alter the relationship between the public services and the public (Giddens, 1997). Partnerships are part of the logic of stakeholding, while the growth of cross-cutting agendas and a holistic approach to service provision carry that logic a little further. For local authorities, the white paper "Modernising Local Government" (DETR, 1998) set the agenda, seeking to embed consultation and participation in the culture. In the same vein, the Social Exclusion Unit claimed *"...the most effective interventions are often those where communities are actively involved in their design and delivery..."* (Social Exclusion Unit, 2001:p.19). The issue for my research is whether in the health service there is the same agenda or belief in the importance of participation. The logic of partnership suggests that a similarity of values and beliefs are important ingredients of success, but one of my informants observed that the local authority has professionals (community workers) whose job centres on developing involvement and who have the flexibility and autonomy to work outside the local authority culture. The health service has very few people who work in this way.

Those who participated in decision-making groups had more involvement and were influential in making decisions in Knowle West. In decisions

about services in the Health Living Centre, the influence of local people was crucial in establishing complementary therapy, against the wishes of the local medical professionals. This was certainly the most successful challenge to the predominant structures found in the research. The fact that the healthy living centre programme was funded by the New Opportunities Fund, rather than the Department of Health probably had a lot to do with their success in challenging the views of the doctors. Without the historical dominance of the medical profession evident in the NHS, NOF was more prepared to respond uncritically to local demands and accepted the local argument for tackling stress through complementary therapies.

The "intrusion" of NOF, SRB & other regeneration into the health arena challenges the dominance of the medical model. In a sense they occupy a vacuum in that the NHS spends only two percent of its budget on prevention or public health (Office for National Statistics, 2003), but by re-defining health, they create another locus of power distinct from the medical-managerial NHS. The NOF approach is characterised by an apparently bottom up approach to planning. Community involvement is "expected" in all aspects of development and delivery (NHS Executive, 1999) and re-definition of knowledge to increase the value given to local perspectives and reduce the reliance on the positivist approaches favoured by the medical profession and NHS managers.

The impact of partnership working can be seen in Knowle West, where for some decisions, particularly early in the process, when the "band of brothers" were involved and later in the preparation of the NOF bid for funding for the healthy living centre, the views of local citizens were decisive. A distinctive feature of the Knowle West project was the early involvement of local people by public sector managers who were enthusiastic about public involvement. Their willingness to take their lead from the views of local people meant that there was involvement in

determining the philosophy of the project. Rowe and DeVanney (2003) conclude that success in partnership has more to do with the relationship between individuals than those between organisations. This conclusion may be borne out by the experience in Knowle West as at later stages, after the initial development, involvement was maintained through the efforts of a group of workers from health and local authorities who were able to span the boundary between local people and service managers. One informant concluded that these specialists (who were mostly community development professionals) are divorced from service delivery and not associated locally with "the Council". This marked out the local authority approach to involvement and contrasted their approach with that of the health service who relied on those who were planning or delivering services to engage local people. So the relationship between the health service professionals and the public is focused on the service delivery, while local authority services are delivered by one group of professionals and involvement is achieved by another. In terms of involvement also, there are differences between health and other public services. Area-based initiatives tend to see the involvement as a goal of investment, with the results seen in terms of changes in people, including community cohesion, empowerment and capacity building (Burton et al, 2004). In contrast, in the health service, there is a tendency to focus on changes in the quality of services resulting from involvement (Crawford et al 2002; Rowe & Shepherd, 2002)

The involvement of citizens in the strategic development of North Bristol Trust made little impact on the content of their plans, except in that it forced them to confront the issues that they had excluded from their internal planning process. Their assumption that the only issues to concern them were directly related to the provision of medical treatment was thoroughly debunked by local people who were more concerned with issues of environment, including transport, congestion and pollution and economy, including the role of hospitals as major employers. Involvement

was late in the process and was isolated from decision making, meaning that there was no opportunity to contribute to underlying assumptions or to directly confront those who were developing the plans.

Do the partnership agenda and the growth and promotion of active citizenship represent an increasingly pluralistic democracy in the modern state in which the power of discourse can make inroads into entrenched structural power, or is what we see as partnership and public participation a new and different technology of social control in which the third dimensional structural power of the state acts to shape decision-making covertly and at arm's length?

The modern state at the beginning of the twenty-first century cannot be seen as operating as a single entity, but is a complex network of organisations operating with a measure of autonomy. Foucault's notion of governmentality is defined by Schofield (2002) as *"a form of power that sets out to structure the actions of others"* (p. 666). Since the late nineties, partnership has become a feature of the discourse of local governance and central to the modernisation agenda introduced by the Blair government. Giddens (1997, 1999) sees partnership as part of the new relationship between the state and the public, a feature of the third way and central to the "democratisation of democracy". As the policy agenda shifts to address cross-cutting agendas, the ability of government to maintain the control through existing actions declines. As a technology to structure the actions of others, partnership has significant flaws: the relationship between the established agencies of government, like the Department of Health, and the new organisations of governance like the New Opportunities Fund (NOF) and New Deal for Communities (NDC) is one of tension, as are relationships between health and local authorities in some parts of the country, however that tension as Maggie suggests offers a route for the creative involvement of local people at a community level. At other levels, organisations like NOF and NDC act in areas that were

previously the sole province of the Department, and act in them without the controlling influence of organised medicine.

In a similar vein, powerful analyses of the health service from outside the Department of Health like those of Derek Wanless (2004) challenge the viability of the service by highlighting the importance of preventing illness and promoting health which account for less than 2 percent of the NHS budget.

Together, these represent the emergence of new loci of control that has come about as a result of partnership working. While the state continues to structure action through the bureau-professional NHS and through the Lukesian professional dominance, it also works through the more pluralistic, less controlled mechanisms developed by New Deal for Communities and the New Opportunities Fund. "Cross-cutting" agendas have the effect of undermining the professionals as the main source of expertise in health. It is the idea of partnership that underpins the New Labour approach to government and it is within the context of partnership that local people are able to become free of the traditional structures of control.

At the local level, the traditional NHS approach to planning creates apathy and mistrust by disempowering local people. Examples like the closure (and proposed re-opening) of community hospitals and the thirty-year wait for a hospital in South Bristol (raised by Knowle West residents as it has been by residents of South Bristol for all of those thirty years) feed a lack of confidence in local health service decision-making structures. The NHS tends not to work well in partnerships because it finds it hard to accept that health issues overlap with other policy areas or that other agencies have a legitimate input into health policy. In North Bristol, the professional definition of needs was challenged by members of the public on the grounds that it omitted important aspects of the hospital development, including the environment and the economy. In Knowle West, local GPs

were unwilling to accept the importance of alternative approaches to stress reduction because they had not been shown effective by research that conformed to their limited view. Managers, influenced equally by the lack of evidence were also suspicious of its value.

Although there appeared to be substantial support from managers in the Somerset Partnership Trust, the reality is that the commitment was limited. The national agenda for change in mental health meant that service users supported much of the initial policy development however financial problems put pressure on management to take decisions without involving or consulting users. As Rhodes and Nocon (1998) point out, there are inevitable tensions between service providers and users when resources are under pressure.

An interesting distinction is that made by Charles, that his primary care organisation was *incorporated* into the North Bristol Trust's programme of development, rather than being seen as a partner. This was a surprising revelation as primary care development was as much a part of the Trust's model of care as hospital medicine, but it exposes the reality of the Trust's limited vision. What appeared to be a partnership, with broad representation at Programme Board level was seen by a major stakeholder as a means to an end for the Trust. Partnerships are organisational forms that are constituted by more or less formal linkage between existing organisations for the purpose of addressing what are perceived as common goals. As Charles' comment suggests, perception of roles is important. In some instances, for example in establishing Local Strategic Partnerships (DETR, 2001), there is a mandatory development, forcing organisations together to work towards "joined-up" government. At other times, such as in the development of neighbourhood renewal, and very specifically at the Knowle West Health Park, more formal partnerships have been accompanied by less formal arrangements that have brought together people from different organisations to achieve change.

In formal partnerships arrangements, Atkinson (1999) sees the reproduction of existing hierarchies as the powerful organisations determine the rules and conventions and legitimate the contributions of partners (Clegg, 1989). This is evident in the involvement of mental health service users in the JCB in Somerset. The need for extensive preparation on the part of service users in order to understand and criticise the papers prepared by managers suggest that a mode for expressing the power and reproducing their hierarchy within the JCB was the institutionalised language of the powerful organisations, the Health Authority and the Local Authority (Bourdieu, 1981). In order to have an impact in decision-making forums, service users and citizens may have to adopt the institutional language and way of thinking and working (Atkinson, 1999). The difficult choice for the community or service user representative can then be to assent to the Board view (which may be counter to personal beliefs and lead to a loss of credibility among other service users), as in the case of the user member of the Partnership Trust Board in Somerset, or to dissent and be marginalised within the Board. There are alternative scenarios however. Where the partnership brings together partners who are uncomfortable with each other, as local health services and local government are in Bristol, this can create a space for local or voluntary sector participants to influence agendas, but this is not possible with the corporatist elite described in Somerset (Peck et al, 2001). It may also be possible to challenge the mode of rationality both through direct expression at meetings (as Kelly or the health action group did in Knowle West), through challenging the formality of meetings, employing boundary spanning workers as advocate/interpreters, or through alternate sources of legitimate authority, *"New, destabilising elements from without"* (Milewa et al, 2002: p. 798) such as the NOF.

The NHS as an organisation maintains power and control by regulating access to decision-making processes. This includes both regulating the

amount of participation and controlling the mode of participation. In the case of indirect involvement, the process for control is in the mediation of participation through summarising and presenting the results of participation at decision-making and minimises the opportunity for challenge to decisions.

In direct participation, there is more opportunity for challenges to decisions and structures, but the health service attempts to maintain control through the imposition of rules, customs and procedures, in formal meetings. Structural power is constructed and maintained through implicit and explicit rules, knowledge and values, (Pellizoni, 2001; Clegg, 1989; Atkinson, 1999). My informants confirm that a significant barrier to involvement is the process through which decisions are made. The formal meetings culture taxes, bores and confuses participants. When these conventions become weakened as they were in Knowle West by the informality of early meetings, through direct challenges in later examples, or through managers relinquishing control as has happened both in Knowle West and at a local level in Somerset, the influence of the public and service users is increased. Where the public and service users accepted the process without modification, as they did in other examples from Somerset, this led to compromise on the part of service users.
As Stewart (2002) points out these examples represent the exercise of third dimensional power in the decision-making process. Control over the form and practice of involvement are elements of the structural power of the agencies of the state to shape policy.

Where other challenges have been forthcoming, they have been deflected by referring to responsibilities in the case of decisions over closure of rehabilitation beds in Somerset or with reference to assumed superior knowledge and expertise in the case of North Bristol. In both cases, the failure to really expose the decisions made by the two Trusts to rigorous

public scrutiny led to conflict, as Foucault says, where there is power, there is resistance (Foucault ,1994).

9.7 Conclusion

This is a clear and growing demand for local accountability in decision-making, which has not been achieved to date, even more than a decade after the publication of "Local Voices" (NHS Management Executive, 1992) Medical control over health service decision-making remains deeply embedded in the culture of the health service and represents a significant disabling influence on public involvement. The willingness to accept knowledge derived from research rooted in positivist traditions as having more inherent validity than the experiences of service users or citizens means that health service managers tend to adopt simplistic and linear explanations of causality and input them directly into the decision-making process in preference to broader views.

We see this most clearly in the North Bristol case study, where local views which contributed cogent, consistent and valid objections to the Trust's plans, which were dismissed, but it is also evident among some health service managers in the Knowle West case study and in Somerset there remains the same tendency. The new arrangements, while conferring a duty on all health organisations to involve the public, do so by creating separate organisations with that purpose. What links there are appear too weak to begin to bring about change in the approach to involvement or the value placed on lay knowledge by the health service. The experience of Knowle West Health Park and other partnership based work including Health Action Zones is that it is possible to increase the role that local people have in decision-making, but that participation has to be central to the ethos of the partnership and there have to be developed processes for influencing policy.

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Appendix

Survey Questionnaire

Public Involvement in Health Service Decisions

A Survey of Health Authorities

In Association with

AVON HEALTH AUTHORITY

NHS Executive South and West

Public Involvement in health service decisions

Please answer questions as fully as you can. Additional material such as reports and policy documents would help with the research, please send copies with your questionnaire if you can. "The public" for the purposes of the questionnaire can be taken to include all people who live in the Health Authority area, whether or not they are or have been users of health services.

Section One: The Organisational Context

Health Authority

Name and job title of person completing questionnaire

In your Health Authority, what is the title of the person who leads public involvement work?

In the last year, how often have public involvement activities or policies been on the agenda for Health Authority Board meetings?

Never ☐ Occasionally ☐ Often ☐ Every meeting ☐

Has the Health Authority established any core principles or values which guide decision making?

Yes ☐ No ☐ Under consideration ☐

If "Yes", how were these principles arrived at and who was involved?

Has the Health Authority adopted any policies or strategies for developing public involvement in decision making?

Approved ☐ Under consideration ☐ None planned ☐

If a strategy has been developed, please describe the process by which this happened and who was involved.

About how many people have public involvement as part of their duties in each of these categories of staff and members?

Non-executive directors ___

Executive directors ___

Senior managers ___

Admin & clerical ___

Are there any committees, working groups or other structures which advise on or control public involvement activities in the Health Authority?

Yes ☐ No ☐

If "Yes", which of the following people are members of the group?

- ☐ Non-executive directors
- ☐ Executive directors
- ☐ Senior HA managers
- ☐ Other HA staff
- ☐ CHC Representatives
- ☐ Others (please say who)

Which of the following have actively taken part in public involvement activities in the last year? (ie have taken part in meetings with members of the public aimed at involving them in decision making)

- ☐ Chair of the HA Board
- ☐ Non-executive directors
- ☐ Chief executive of the Health Authority
- ☐ Other Executive directors
- ☐ Senior managers
- ☐ Other HA staff
- ☐ Other people (please specify)

Section Two: Public Involvement Activities

There are a range of ways in which the public can be involved in decisions. Which of the following have your Health Authority used

Public meetings ☐
Usually formal meetings at which proposals are presented for discussion

Stakeholder conferences ☐
Often large scale meetings of service users, providers of care, commisisoners and other stakeholders who have an interest, with an aim to reaching a consensus on health or health service issues.

Opinion surveys ☐
Face-to-face, telephone or postal surveys of the local public

Planning forums ☐
In which service users take part in meetings with managers and planners

Focus groups ☐
Small group meetings in which people are invited to discuss a given issue or issues

Health interest groups ☐
Meetings with groups concerned with health issues which already exist in the local community

Standing panels ☐
A representative sample of the local population who are regularly asked for their opinion on health and health service issues

Health panels ☐
Small groups of people who meet, often on several occasions to discuss health and health service issues

Citizen's juries ☐
Formal panels who meet over several days to hear evidence and give opinions about a particular health issue

Community development ☐
Work with local communities to build confidence, develop support structures and promote active participation in community activities

Other (please describe) ☐

Have Health Authority staff involved in these activities received any training in preparation for taking part? If so, please specify.

Yes ☐ No ☐

Section Three: The Impact of Involvement

Over the last five years, your health authority may have involved the public in service reviews or planning decisions in some of these areas. Please make an assessment of the influence of the views of the public on the final decisions taken or policies agreed. The impact should be assessed on a scale of 1 to 5, where 1 is least influence and 5 is most. Space is given to add other services.

Accident & Emergency	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Closure of a hospital	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Cancer	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Community nursing	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Diabetes	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Elective surgery	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Emergency admissions	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Family planning	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Health promotion	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
HIV/AIDS	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Learning difficulties	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Maternity	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Mental health	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Oral health	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Primary care	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Services for elderly people	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Services for physically disabled people	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
_____	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
_____	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
_____	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

For one of the pieces of work assessed for the previous question, please describe the steps taken to ensure that the views of the public were considered by those making the final decisions.

Section Four: Other Issues in Public Involvement

In planning public involvement, has the health authority worked with any of the following organisations (mark all that apply)

- NHS Executive ☐
- NHS Trusts ☐
- Community Health Council ☐
- Primary care ☐
- Social services ☐
- Other local government ☐
- Professional organisations ☐
- Voluntary sector umbrella groups ☐
- Other voluntary sector ☐
- Academic institutions ☐
- Private sector experts ☐
- Others ☐

Is there an annual budget identified for public involvement work?

Yes ☐ No ☐

If so, how much? £ ☐ 000

Have any of your public involvement activities been evaluated?

Yes ☐ No ☐

Please send copies of any evaluation reports which are available.

Please Use this space for additional comments

This survey is being undertaken as part of a broader programme of research on public involvement in the health service. Subsequent stages will involve more detailed work with a small number of health authorities. Would your health authority be prepared to participate in this work, which is likely to involve face-to-face interviews and, in some cases, focus group discussions?

Yes ☐ No ☐

If you would be prepared to take part, please provide the following contact information

Contact Name

Phone number

Fax

Email

Thanks very much for your help!

Please return this form to:

Michael Shepherd
Research & Development Manager
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